

**THE EMOTIONAL EXPERIENCES OF PATIENTS FOLLOWING
REMOVAL OF THE EYE (ENUCLEATION OR EVISCERATION)**

by

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DECLARATION

I declare that **THE EMOTIONAL EXPERIENCES OF PATIENTS FOLLOWING REMOVAL OF THE EYE (ENUCLEATION OR EVISCERATION)** is my own work and that all the sources that I have used or quoted have been indicated and acknowledged by means of complete references and that this work has not been submitted before for any other degree at any institution.

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14TH JUNE 2007

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ABSTRACT

There is a growing recognition that removal of an eye may cause a significant impact on a person's body image and her or his role in society; and may evoke a variety of emotional responses. The loss of an eye does not only signal disfigurement, it also means a loss of a body part and a vital sense; that of sight. Without vision, individuals have difficulty communicating. The emotional responses to this loss many a times, go unrecognized as the doctors and nurses who are in close contact with the patient at this time are not necessarily prepared to provide emotional care. This study seeks to address this gap by identifying the emotional impact of loss of an eye and sight on people's lives and the implication it has for health care workers, especially nurses. The eliciting of the different feelings and experiences of these patients can provide information for the formulation and design of protocols for holistic health care management.

A non-experimental exploratory and descriptive design was used to conduct In-depth conversational interviews with seven purposively selected participants who had enucleation or evisceration between 2000 and 2005. Information-rich data yielded findings that clearly stressed the need for greater sensitization to the problem. All the participants expressed shock at the final diagnosis of enucleation or evisceration even if this was on their request. Patients wanted to know about the operation and its outcome, the prosthesis, how will it look like and its fit. Findings indicate that answers to these questions were not provided. Patients were not adequately emotionally prepared pre-operatively and were therefore not appropriately cared for post-operatively. Families were not satisfactorily involved and as such were not in a position to provide emotional support that the patients needed

The recommendation was that a study to explore the health care team's knowledge in the psychological and emotional management of patients in crisis should be conducted as a benchmark for further training.

KEY TERMS

Enucleation; emotion; evisceration; experiences; eye; patients.

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DEDICATION

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List of Abbreviations

BR	Sir Benjamin Rycroft Ward
CPU	Corneo-Plastic Unit
CSBPS	Community Services for the Blind and Partially Sighted
GP	General Practice
GP	General Practitioner
NHS	National Health Services
OPU	Oculo-Plastic Unit
QVH	Queen Victoria Hospital
RNIB	Royal National Institute of the Blind
SA	South Africa
UK	United Kingdom

Ocular Terminology

Anophthalmos: Absence of the eye. It can be a congenital or an acquired condition

Asymmetry: Imbalance in facial alignment as it relates to the eyes or eyelids.

Buphthalmos: An autosomal recessive trait characterized by an increase in the corneal diameter (12 mm) which occurs as a consequence of congenitally increased intraocular pressure. Onset could be at birth or before the age of 3 months. It is also known as 'infantile glaucoma'

Conformer: A temporary concave or oval shaped prosthesis most commonly made of clear acrylic material. It is placed into the socket following enucleation or evisceration for socket reconstruction. It aids in retention of the upper and lower cul-de-sac, and to prevent inversion of the eyelashes. It also has two small holes to allow drainage of secretions and to apply post-operative antibiotics.

Cosmesis: Mirror image symmetry of the eye and lids; a return to a normal appearance.

Endophthalmitis: Is an inflammation of the inside of the eye, including the central part of the eye, which is filled with a clear gel-like substance, called the vitreous. The inflammation affects the surrounding tissues that are responsible for vision. Post-operative endophthalmitis occurs most commonly after cataract extraction, which presents with sudden onset of progressively worsening vision, pain, and a red eye.

Enophthalmos: The overall sinking appearance following the loss of the eyeball, or partial loss of ocular volume.

Exenteration: Removal of the orbital contents which could include the eyelids.

Exophthalmos: Abnormal protrusion of the eyeball.

Extrusion: An expulsion of an orbital implant.

Glaucoma: Is an ocular condition in which there is loss of visual function of the cones, resulting from the sustained elevation of intraocular pressure.

Implant: Any inert foreign or autogenous material embedded within the living tissue in the orbit. It is a prosthetic device of glass, metal or human tissue materials, which is surgically inserted at the enucleated eye.

Impression Moulding Technique: An adapted version from the dental profession for obtaining an accurate copy of anophthalmic socket, and/or affected eye with a suitable impression tray.

Lagophthalmos: Voluntary or involuntary (Incomplete) closure of the eyelid.

Macrophthalmos: an abnormally large eyeball, usually related to infantile glaucoma.

Microphthalmos: A congenital anomaly where there is partial developed eyeball of the eyeball resulting in a small eye. The condition can be hereditary.

Monocular: Single vision.

Mucus: Is a clear, sticky secretion of the mucous membrane, consisting of mucin, epithelial cells, leucocytes, and various organic salts suspended in water.

Ocularist: A paramedical technician who fabricates and fits custom made artificial eye.

Ocular Terminology

Ocular prosthesis: It is an artificial eye used when an eye is surgically removed.

Ophthalmologist: A medical physician who specializes in diseases and defects of the eye and its adnexa.

Panophthalmitis: Acute suppuration of the inner eye with necrosis of the sclera (and sometimes the cornea) and extension of the inflammation into the orbit. Pain may be severe and the globe may rupture.

Phantom eye syndrome: Refers to phantom phenomena, such as phantom pain in the eye and visual hallucinations, after removal of an eye (enucleation, evisceration).

Phthisis/Phthisical: Phthisis and Phthisical refer to an eye that has shrunk due to loss of fluid. This acquired condition is caused by a disease, trauma or surgery.

Proptosis: Protrusion of the eye.

Pseudoptosis: A sagging or drooping of the upper eyelid. This is a result of orbital or global volume loss, but returns to normal elevation with a proper fitting of an ocular or scleral prosthesis.

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 - Permission to conduct research study from the ward manager: Sir Benjamin Rycroft
 - Permission to conduct the research from the Corneo-Plastic Unit Consultant (CPU)
 - Permission to conduct the research from the West Sussex Local Research Ethics Committee
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 - Letter from the Oculo-Plastic Consultant
 - Letter from the director of Nursing QVH NHS Foundation Trust
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 - Approval from West Sussex Research Ethics Committee
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CHAPTER 1

Orientation to the study

1.1 INTRODUCTION

Removal of an eye, whether through evisceration or enucleation, causes a significant impact on a person's body image and role in society. It evokes a variety of emotional responses to the loss not only of a body part but also of a vital sense, namely sight. Tolley and Henninger (1991:18) and Sen (2005:1) point out that removal of an eye fills most patients, many ophthalmologists and nurses with horror. Patients fear the loss of visual function as well as the cosmetic implications of a prosthesis (glass eye). Tolley and Henninger (1991:18) found little evidence in the literature to suggest that the important aspects of emotional care were recognised, addressed or catered for by health care professionals. Some people therefore might inadvertently reinforce those negative perceptions when they talk about losing one or both eyes.

Sen (2005:18) states that some patients suffer pain and poor cosmesis for a long time, in which case removal of a diseased eye might be regarded in a positive light. The focus should be on providing the patient with an ideal socket. However, Migliori (1999:99) emphasises that enucleation or evisceration could elicit a range of complex emotional responses. Whatever the reason for those procedures, the permanent bodily change causes a sense of loss and altered self-image in patients.

Morris (1991:25) describes evisceration as the surgical technique in which the entire intra-ocular contents are removed, leaving the conjunctiva, the scleral shell and the extra-ocular muscle attachments intact. An implant may later be inserted. This procedure is carried out post-trauma, for a blind painful eye and in severe infections of the eye, like panophthalmitis and endophthalmitis, to prevent spread of infection to the brain via the optic nerve and blood vessels (Kitzmann, Weaver, Lohse, Helmut-Buettner & Salomao 2003:594). The above procedure offers good natural motility to the anophthalmic socket. According to Hehir (2000:9) and Bilyk (2000:380), evisceration has an advantage in that it provides a functional and cosmetically acceptable orbit when compared to enucleation. The intact sclera provides an excellent barrier to orbital spread of infection in cases of endophthalmitis.

Enucleation, on the other hand, is the surgical removal of the entire eyeball (globe) together with a portion of the optic nerve and the conjunctiva (Hehir 2000:9). This is the oldest ophthalmologic operation and continues to be the treatment of choice in advanced malignant tumours of the eye. Enucleation may be performed in the case of extensive injury to the eyeball, intra-ocular malignant tumours, or where there is no reasonable chance of visual recovery. Diseases such as glaucoma or corneal ulcers, where a patient suffers intense pain and discomfort, are also good indications for such an operation. It has the benefit of preventing sympathetic ophthalmia.

Migliori (1999:99) points out that losing a part of the body, such as an eye, is a traumatic and distressing experience. Therefore, grieving would occur and adjustment to loss varies among people. The researcher therefore wished to explore and describe the emotions that patients with the loss of an eye and sight experience and express.

1.2 PROBLEM STATEMENT

Eyes, as vital organs, perform a crucial role in communication, signalling to others when speaking and listening to them. Eyes are also an important part of physical attractiveness and are important to a person's self-image and self-esteem. Clarke, Rumsey, Collin and Wyn-Williams (2003:35) maintain that despite an increased understanding of the difficulties faced by people with a range of disfiguring conditions, little is known about the emotional problems encountered by patients with eye conditions. The impact of injury or disease that affect the eye, even in instances where quality of life measures have been employed, has been studied almost exclusively in terms of the effects on vision. Given the role of the eyes in both communication and perceived physical attractiveness, little is known about the emotional impact of enucleation or evisceration.

This study sought to explore and describe patients' emotional experiences following removal of an eye either through evisceration or enucleation.

1.3 BACKGROUND TO THE PROBLEM

Of the five human senses, sight has always been considered the most important. It has long been acknowledged, however, that vision loss might bring about varying and greater degrees of

psychic suffering much more than any other form of sensorial impairment at all ages (De Leo, Hickey, Meneghel & Cantor 1999:339).

De Leo et al (1999:339) emphasise that the loss of an eye is a devastating experience and the response to blindness is a grief reaction in which the patient mourns the loss of sighted self. Patients become concerned for their emotional, psychological, physical well-being and quality of life. People who have not personally experienced a loss of this nature can only imagine what it must be like. Often, when people are unfamiliar with an emotional situation, they do not know what to say or how to act. This loss of control and lack of understanding about their own feelings and actions leads to fears and anxieties that are expressed as self-pity, irritation, anger, guilt, rudeness and inattention (Lyons, Jacobson, Prescott & Oswalt 2002:3).

Clarke and Wyn-Williams (2000:14) find it surprising that disfigurement that affects the eye has been largely overlooked, considering that the central role of the eye is both communication and perceived physical attractiveness. For people with disfiguring conditions affecting the eye, social interaction might be complicated by the role of the eyes in communication, and as an important determinant of sexual attractiveness. Therefore, a time for mourning is needed for sight loss, as the loss includes the loss of a significant body part as well as mobility, appearance, self-sufficiency, economic security and some contact with reality.

According to Sethi, Tyagi and Mohta (2003:17-18), body image is people's conscious and unconscious concept of the physical appearance of their body. It contributes to the sense of identity, and for patients who have lost an eye and sight the threat of harm to body image is severe. They experience an altered state of consciousness due to either physical or emotional causes. Emotional causes are usually based on defensive dissociation to avoid emotionally painful situations.

According to Morris (1991:26), evisceration or enucleation is performed in cases of

- severe glaucoma (high intra-ocular pressure)
- malignancy of eye structures such as Melanoma
- infections such as endophthalmitis
- severe trauma

These situations are emotionally devastating and challenge nurses to provide quality emotional support and assist the patients to adapt to the situation.

Vader (1992:712-713) maintains that because adjustment to loss varies greatly among people, nurses must be aware of the behaviours and emotions that visually impaired persons experience.

One of the biggest challenges facing ophthalmic nurses is to provide quality emotional care for patients admitted for surgical removal of an eye. Nurses are faced with situations in which they need to take a leading role to meet the needs, especially emotional needs, of these patients. Tolley and Henninger (1991:18) maintain that although nurses are empathetic, they are not prepared for dealing with the emotional state of patients who experience loss of both the eye and sight as well as protection of the remaining eye. De Leo et al (1999:339) found that research into the emotional impact of sight loss tended to focus on clinical-diagnostic rather than therapeutic-preventive aspects.

The above background motivated the researcher to explore the emotional experiences of patients who had undergone removal of an eye through enucleation or evisceration.

1.4 PURPOSE OF THE STUDY

The main purpose of this study was to gain an understanding of and insight into the emotional experiences of patients who had undergone enucleation or evisceration in order to elicit the patients' feelings and emotions. In addition, with this knowledge, the researcher wished to, in future, formulate protocols and mechanisms for coping and support systems that would enable nurses to provide the care that the patients need.

1.5 RESEARCH OBJECTIVE

The objective of this study was to explore and describe the patients' emotional experiences following the loss of an eye through enucleation or evisceration

1.6 RESEARCH QUESTION

The study answered the following question:

What are the emotional experiences of patients following the removal of an eye?

1.7 SIGNIFICANCE OF THE STUDY

Losing an eye and sight impacts profoundly on people's lives and has several implications for nurses and health care workers. Exploring and validating the different feelings and behaviours of these patients would provide information for reviewing existing policies on caring for patients before and after surgical removal of the eye. The study would also identify mechanisms and strategies for coping with partial or complete loss of sight and make recommendations on support systems to enable ophthalmic nurses to identify emotional needs and provide good quality emotional care to such patients.

1.8 ASSUMPTIONS

Assumptions are basic principles that are assumed to be true based on logic and reason, without proof or verification (Mouton & Marais 1990:11; Polit & Beck 2004:13-14). Sources of assumptions include universally accepted truths, such as theories, previous research and nursing practice. In research studies, assumptions are embedded in the philosophical base, study design and interpretation of findings (Burns & Grove 2005:46).

To this end, epistemological, ontological and methodological assumptions were posited in this study.

Mouton and Marais (1990:14-15) define **epistemological** assumptions as statements that embody the ideal of science, namely the quest for truth. Following the lead of Greek philosophy, it was customary to regard certainty and demonstrable proof and knowledge. Although it is difficult to ascertain when the truth has been attained, it is, however, necessary to strive that the findings should approximate reality as closely as possible. In this regard it is assumed that individuals are essentially holistic beings therefore:

- Emotional patient care is an essential component of holistic nursing practice.
- Narrative data can elicit an understanding of the meanings that patients attach to emotions following enucleation or evisceration.
- Concepts related to emotional experiences inductively generated from data are likely to offer insight, enhance understanding and provide a meaningful guide to action for nurses and other health care workers working with patients who have suffered the loss of an eye(s).

Ontological assumptions refer to the study of being or reality (Mouton & Marais 1990:11-12). In naturalistic paradigms, the “inquirer interacts with those being researched; and the findings are the creation of the interactive process” (Polit, Beck & Hungler 2001:13).

This study was based on the following assumptions regarding reality:

- Human nature has an emotional dimension, which encompasses the need to have meaningful and helpful relationships in times of loss.
- Emotional needs are often fulfilled within an environment of an organised system of support whether formal or informal.
- All persons are valued as emotional beings regardless of their age, marital status or occupation.
- The holistic approach to nursing care entails meeting the physical, psychosocial and emotional needs of patients.

According to Mouton and Marais (1990:15-16), **methodological** assumptions concern what may be called the ‘how’ of social sciences research. In other words, how should research be planned, structured and executed to comply with the criteria of science. It refers to the logic of implementing scientific methods in the study of reality.

This study was based on the following methodological assumptions:

- Qualitative research supports the generation of rich data necessary to develop categories and emerging themes for clarity on what the loss of an eye or eyes means to the respondents.
- Qualitative research supports the collection of narrative data in order to elicit information about the emotional experiences of patients whose eyes have been surgically removed, from an insider perspective.
- Qualitative research would enable the researcher to understand how individuals interpret their world in the context of the loss of one or both eyes.
- Approaches can be applied to verify the accuracy of information either with the informants or triangulating among different sources of information (Creswell 1994:7).

1.9 DEFINITION OF KEY WORDS

For the purpose of this study, the following terms were defined as indicated below.

- **Emotions**

Ross (1997:1) refers to emotions as subjective feelings that are essentially private experiences. Anderson and Phelps (2002:709) state that emotions are conscious experiences people undergo corresponding to specific affective states, such as sombre feelings associated with sadness or the elation associated with joy. Hudlicka (2000:1) adds that emotions are a means to communicate with oneself and others.

Emotions are strong feelings such as anger, fear, grief, joy, or love or aroused mental state recognised in some people by bodily changes, and in others by certain characteristic behaviour (Freshwater & Maslin-Prothero 2005:205).

According to Huang and Alessi (2003:148), emotions are an essential part of how people experience the world. Emotions have multiple aspects and form a significant part of all of people's subjective and automatic responses. Emotions affect all behaviours, cognitions, conscious and unconscious interactions between individuals and the environment.

In this study emotions are described as feelings expressed by individuals following the loss of an eye and sight before and after surgery.

- **Emotional experiences**

Hupfeld (1999:157) holds that emotional experiences are conceptualised as individualised dispositions to respond emotionally to various situations. Different people experience different emotions in similar situations. Hupfeld (1999:157) adds that emotional experiences depend on the specific personal goals, motives, or concerns that are affected by the situation; that is, what is experienced as joyful or happy, or as sad or angering depends on the receptive construal of self.

Emotional experiences are fluctuations in emotional expressions that are beyond the person's control, and may shift from crying to laughing, from anger to fear (Freshwater & Maslin-Prothero 2005:205).

In this study emotional experiences refer to responses, incidents, activities and challenges that people who have lost an eye (or both eyes) and sight can express through anger, guilt, shock, denial, hopelessness or helplessness.

- **Enucleation**

Hehir (2000:9) describes enucleation as “the surgical procedure that involves the removal of the entire globe by severing the attachments of extra-ocular muscles and the optic nerve”.

Mosby’s Medical Nursing and Allied Health Dictionary (1994:543) defines enucleation as “the removal of an eyeball, performed for malignancy, severe infection or extensive trauma or to control pain in glaucoma”. In this study enucleation refers to removal of the entire eyeball (globe).

- **Evisceration**

Kitzmann et al (2003:594) describe evisceration as “the surgical procedure that aims at removing the contents of the eye only and leaving the sclera and the extra-ocular muscles intact”.

Dorland’s Dictionary (1994:588) defines evisceration as “the removal of the contents of the eyeball with the sclera being left intact”.

In this study evisceration refers to the complete evacuation of the intra-ocular contents while preserving the sclera shell and the extra-ocular muscles.

- **Experience**

Pearsall (1999:501) defines experience as “the knowledge or skill acquired over time; an event or occurrence that leaves an impression on one”.

In this study experience draws on the feelings and knowledge of the impact and consequences of eye and sight loss acquired over time by patients who have had their eyes removed due to sickness, infection or injury.

- **Eye**

Mosby's Medical Nursing and Allied Health Dictionary (2001:456) defines an eye as "an organ of sight contained in a bony orbit at the front of the skull, embedded in orbital fat and innervated by one of a pair of optic nerves from the forebrain".

Montgomery (1998:1) describes the human eye as "the organ that gives people a sense of sight, allowing them to learn more about the surrounding world than they do with any of the senses. The eye is used in almost every activity that is performed, whether reading, working, watching television, writing, driving a car, and countless other ways. Most people agree that sight is the sense they value more than all the other senses."

In this study an eye is described as a complex organ of sight, used for communicating with others and also compliments physical appearance.

- **Patient**

A patient is "a person who is physically or mentally ill or who is undergoing treatment for physical or mental illness" (Freshwater & Maslin-Prothero 2005: 440).

Mosby's Medical Nursing and Allied Health Dictionary (1994:1174) defines a patient as "a name given to any person who is ill or injured and being treated by, or in need of treatment by a physician or other medical professionals".

For the purpose of this study, a patient means a person who has lost an eye, or both eyes and sight following enucleation or evisceration.

- **Ophthalmic nurse**

An ophthalmic nurse is a registered person with the Nursing Council according to the statutory requirements of respective countries. An ophthalmic nurse provides care to persons with disorders of the eyes, including blindness or visual impairment and those who have undergone eye surgery.

In this study an ophthalmic nurse is a professional nurse who provides specific specialised care to persons with disorders of the eyes, including blindness or visual impairment

- **Sight**

Freshwater and Maslin-Prothero (2005:554) define sight as “the act of seeing or ability to see. The special sense involved in seeing.”

Mosby’s Medical, Nursing and Allied Health Dictionary (1994:1435) describes sight as “the special sense that enables the shape, size, position and colour of the objects to be perceived”.

1.10 RESEARCH DESIGN AND METHOD

1.10.1 Introduction

The researcher undertook a non-empirical explorative qualitative study to describe and better understand the lived emotional experiences of patients who had undergone surgical removal of their eyes and the meaning attached to it. Langford (2001:138-139) defines qualitative research as “an objective way to gain insights about the subjective and holistic nature of man”.

In qualitative research people are perceived as conscious, self-directing beings who are continuously constructing, developing and changing their everyday interpretations of their worlds in order to make sense of their lives. Qualitative research relies heavily on the inductive reasoning process and seeks to examine and understand the whole of the phenomenon.

The focus is on the process by which concepts are given meaning in a given context rather than on the measurement of the concepts and their relationships (Tjale & De Villiers 2004:239). Qualitative researchers emphasise the inherent complexity of humans; the ability to create their own experiences, and the idea that truth is a composite of realities. The focus is on understanding the human experience as it is lived. In qualitative research the investigation is typically in-depth and holistic, through the collection of rich narrative materials (Polit & Beck 2004:15-17).

To conceptualize emotional experiences from the perspective of patients who have suffered the loss of one or both eyes, within the ophthalmic health care context, requires an approach that will capture the insider’s knowledge, freedom of expression without boundaries and natural

representation (Henning, Van Rensburg & Smit 2004:3). The phenomenological research tradition provided the theoretical underpinning for this study.

The research methodology will be discussed in detail in chapter 3.

1.10.2 Research setting

The study was conducted in the Corneo-Plastic Unit at the Queen Victoria Hospital National Health Services Foundation (NHS), London, United Kingdom (UK). The Corneo-Plastic Unit and its expanding Oculo-Plastic services provide care across a wide spectrum of ocular health with particular emphasis on complex corneal diseases. The Unit is dynamic, flexible and proactive in all aspects of ophthalmic care.

1.10.3 Research design

The research design refers to the plan and procedures to be used to accomplish the purpose and specific aims of the study. Talbot (1995:440) describes a “research design as an overall plan for answering research questions and strategies for gathering data. The design also determines how the data will be collected and analysed.” In this study a qualitative approach using a non-experimental, exploratory and descriptive research design was deemed appropriate to explore and describe the patients’ experiences following removal of an eye.

A core question was asked to initiate a discussion that was to obtain patients’ deep-seated views on their emotional experiences following the removal of an eye. The discussion would explore the participants’ concerns, strengths, and difficulties in social functioning, coping strategies, and levels of perceived emotional support (Clarke et al 2003:36).

Bracketing was applied throughout the study to improve rigour and reduce bias. Brink (1996:120) describes bracketing as the process of identifying and setting aside any preconceived beliefs and opinions researchers might have about a phenomenon under investigation.

1.10.4 Population

Polit, Beck and Hungler (2001:40) define a population as “an aggregate of all the individuals or objects to be studied with some common defining characteristics”. In this study the population

consisted of all the patients who had undergone evisceration or enucleation between the years 2000 and 2005.

1.10.5 Sample and sampling technique

A non-probability purposive sampling technique was used to identify and select seven suitable participants who were willing to share their emotional experiences following the removal of an eye through enucleation or evisceration. The participants were selected on the notion that they were more likely to yield rich information on the subject. Bassett (2001:66-67) points out that qualitative research does not require a large number of participants that are selected randomly because the emphasis is on the quality rather than quantity of data.

The selected sample provided the desired information, but the findings could not be generalised to the population because the sample size was small. Inclusion criteria were that both male and female patients who suffered loss of an eye through enucleation or evisceration and were willing to participate in the study should be recruited.

1.10.6 Data collection

1.10.6.1 Research instrument

An in-depth interview guide was used to collect data. According to Parahoo (1997:294), an interview guide is used to direct the researcher in obtaining information from the participants in their own words. Interviewing was the main data-collection technique. Burgess (1984) (cited in Holloway & Wheeler 2001:79) describes qualitative interviewing as “conversation with purpose”. The purpose of the interview was to discover the respondents’ feelings, thoughts and perceptions about their emotional experiences following removal of the eye. This was important because the respondents’ own framework of meanings was discovered and the researcher avoided imposing her own assumptions as much as possible. The interview guide consisted of one core question followed by possible probing questions. The probing questions were not necessarily sequential but rather dictated by the conversation, as some patients started with the mention of the emotional support or non-support received while others started with fears following the diagnosis (see annexure A).

The researcher remained open to the possibility that the concepts and variables that emerged might be very different from those that had been predicted at the outset.

1.10.6.2 Pre-testing of the instrument

According to Holloway and Wheeler (2001:80), a pre-test is conducted to get used to the application of the instrument and the interview method itself. Therefore in this study, a pre-test was conducted with two patients who had eye surgery at the researcher's place of work to gain insight into the activity and errors found were rectified. A tape recorder was also used to ensure correct usage.

1.10.6.3 Data collection process

Informed consent (verbal and written) was obtained from the respondents before the interview commenced. The purpose of the study was explained, with emphasis on the fact that refusal to participate would not affect their future treatment. The information sheet provided to the respondents explained what was involved in the study and what was expected of them.

The duration of the interview was thirty to forty-five minutes per session. The respondents were assured of confidentiality and privacy. An interview guide was used to avoid losing focus and to ensure that the relevant questions were asked.

Permission was sought from the respondents to tape-record the interviews. The tapes were transcribed verbatim to capture the interview data. A quiet room without disturbance in the Corneo-Plastic Unit was provided and a sign to indicate that interviews were in progress kept control of distractions.

The tape recorder was tested before the interviews were conducted to ensure that it was working properly. Stand-by batteries were provided in anticipation of possible power failure. The tapes were dated and labelled and only pseudonyms appeared on the tape or its transcription. The respondents' names were stored in a different place to the tapes to ensure anonymity and confidentiality (De Vos, Strydom, Fouche & Delpont 2002:304).

Using the tape recorder allowed a much fuller record of the interviews. Taking notes during the interview was also complementary for accuracy of information. With the aid of a tape recorder

the researcher was able to concentrate and focus on the proceedings of the interview and determine precisely where to go next.

However, there were some disadvantages with this method. Some of the respondents did not feel happy about being tape-recorded even after full explanations were made. Such patients, even if they ideally met the criteria for inclusion, were not coerced to participate in the study.

In addition, telephone interviews were used to revisit collected data for accuracy. It was convenient for complementary use where the researcher needed clarification of the comments and the respondents had travelled long distances to the Unit. The telephone verification interviews lasted between ten (10) to fifteen (15) minutes. The advantage of telephone interviews was the respondents' immediacy of response, anonymity and effective use of time. However, the telephone interviews lacked the deeper interaction with the respondents that is required mostly in qualitative research.

1.10.6.4 Data analysis

Polit, Beck and Hungler (2001:380) point out that qualitative data analysis is a labour-intensive activity that requires creativity, conceptual sensitivity and sheer hard work. It does not proceed in a linear fashion and is less structured. It usually focuses on the meaning of the information collected by way of more descriptive interpretations of responses (Del Barrio 1999:2).

Polit et al (2001:459) describe data analysis as “the process of organising and integrating narrative information according to emerging themes and concepts”. Holloway and Wheeler (2002:235) add that the process of analysis goes through certain stages like transcribing and sorting field notes, organising and ordering the data, listening to and reading the material collected over and over again, coding and categorising, building themes and describing a phenomenon.

In this study the researcher collected and analysed data simultaneously. The tapes were transcribed verbatim on a daily basis. Bodgen and Taylor (1975) and Maykut and Morehouse (1994) (cited in Crawford, Leybourne & Arnott 2000:5) state that qualitative research looks at understanding a situation as the participants construct it, captures what people say and do and how they interpret their world. Therefore the researcher needed to capture the participants' interpretation through empathic understanding, while remaining as objective as possible. Tech's

(1990) steps (Creswell 1994:150) for data analysis were followed as guidelines for qualitative analysis.

1.10.7 Measures to ensure trustworthiness

In qualitative research data interpretations must be credible, transferable, dependable and confirmable. Lincoln & Guba (1985:301-331), Siegel (1999:14), and Crawford et al (2000:6-11) describe these four criteria as pertinent for evaluating qualitative findings and enhancing trustworthiness. These criteria are incorporated into the research design and are used to assess qualitative findings:

- **Credibility.** This criterion is an assessment of the believability or credibility of the research findings from the perspective of members or study participants. This was employed by inclusion of member checking into the findings; that is, gaining feedback on results from the participants, and verifying information with the participants.
- **Transferability.** This refers to the degree that the findings can be transferred or generalised to other settings, contexts, or populations. The researcher enhanced transferability by detailing the research methods, contexts and assumptions underlying the study. “Thick description” of these aspects was done as everything was described in great detail.

The sample consisted of participants of different age groups who had had enucleation or evisceration. Dense description of data regarding participants, research context and the setting was provided.

- **Dependability.** This refers to how reasonably researchers can be sure that the findings would be replicated if the study was conducted with different participants in the same context (De Vos et al 2005:345).

Libarkin and Kurdziel (2002:199) maintain that careful review of the process of data collection, analysis and research product, especially as time evolves can help establish dependability. Therefore, in this study data were coded, categories developed and emerging themes identified. Supervisors audited the study, examined and compared the data.

- **Confirmability.** This refers to the extent to which the findings are a true reflection of the participants and the inquiry itself (De Vos et al 2005:345). Can the findings be confirmed or corroborated by others? Strategies for enhancing confirmability included searching for negative cases that ran contrary to most of the findings. A data audit was conducted to pinpoint potential areas of bias, prejudice or distortion. Audit trail, triangulation of data collection methods and bracketing were used.

1.10.8 Ethical considerations

Ethical considerations are important aspects of research when using humans as study participants. Polit and Beck (2004:141) emphasise that care must be exercised to protect human rights at all times. Ethical considerations influence researchers' ability to acquire and retain participants in a study and also safeguard their welfare.

The following steps were followed to maintain ethical standards in this study:

- Permission was obtained from the Queen Victoria Hospital NHS Foundation Trust and Corneo-Plastic Unit.
- The research proposal was reviewed by the University of Brighton to ensure that the required ethical standards were maintained.
- Institutional approval was sought by presenting the research proposal of the study to the Research and Development Committee in Queen Victoria Hospital NHS Foundation Trust.
- The research proposal was presented to the Research and Ethics Committee of the University of South Africa and permission was granted (Academic body).
- The research proposal was presented to the West Sussex Research and Ethics Committee on 24 July and approval was granted on 22 August 2006.
- The participants gave informed consent after the researcher had explained to them that they were free to withdraw from the study whenever they so wished to without any penalty or fear of intimidation. They were also assured of anonymity, privacy and confidentiality of information given as this was only used for the purposes of this study.

The success of an open-ended interview depended on the interviewer's communication skills in keeping the discussion as a relaxed dialogue. These skills helped the participants to feel at ease.

The researcher showed respect for the participants' wishes not to disclose information that they felt was private and sensitive to ensure confidentiality and anonymity.

In this study the researcher intended to directly quote the participants' words. The researcher made it clear that the interviews would be tape-recorded and transcribed without disclosing any names. The participants' names would not be associated with any information disclosed, or any publication resulting from this study, although some of the participants' words might be included in the research report (Morse & Field 1996:144).

1.11 LIMITATIONS AND SCOPE OF THE STUDY

Burns and Grove (2003:42) describe limitations as restrictions in a study that may decrease the transferability of the findings. They may be deficiencies or weaknesses in the research method or design problems.

In this study, most of the patients had had long-standing ocular problems and had requested that surgery be done, which request might have had an impact on the credibility of the responses given.

The sample size was small and therefore the findings cannot be generalized to all patients who have had enucleation or evisceration.

1.12 OUTLINE OF THE STUDY

Chapter 1 outlined the purpose of the study, background to the problem, definition of key words, research design and methodology including sample, sampling technique, data-collection instrument, ethical considerations as well as the limitations of the study.

Chapter 2 covers the literature review conducted for the study.

Chapter 3 discusses the research design and methodology.

Chapter 4 describes the data analysis and the findings of the study.

Chapter 5 presents the conclusions, recommendations and limitations of the study.

1.13 CONCLUSION

This chapter briefly outlined the need for the provision of emotional care and support by nurses for patients who have undergone enucleation or evisceration, and highlighted some of the conditions that make removal of an eye or eyes inevitable. The purpose of the study, research design and methodology were also described and key terms defined.

Chapter 2 discusses the literature review conducted for the study.

CHAPTER 2

Literature review

2.1 INTRODUCTION

This chapter discusses the literature review on the experiences of patients following visual loss. The researcher conducted an extensive literature review on concepts such as emotions, emotional experiences, enucleation and evisceration.

Harlem and Schlapp (1998:1) explains that a literature review is used to inform researchers of the background to research projects and provide context and ideas for the design for new studies. A literature review helps to identify gaps in current knowledge and clarifies what has not so far been systematically investigated and where the focus for further enquiry should lie. At a more detailed level, information gained from reviewed literature can help to formulate research questions as well as clarify and limit the scope of a study.

The literature review covered aspects on patients' emotional experiences of visual loss; the three methods or procedures of removing an eye (namely enucleation, evisceration and exenteration), indications for these procedures and complications thereafter; preoperative care and postoperative management; the impact of loss of vision on patients and their coping mechanisms and the role played by the ophthalmic nurse.

2.2 EMOTIONS

Ortley and Jenkins (1992) (cited in Hudlicka (2000:1) state that emotions are communications to oneself and others. Hudlicka (2000:1) adds that emotions are part of a management system to coordinate each individual's multiple plans and goals under the constraints of time and other resources. Emotions are part of a biological solution to the problem of how to plan and carry out actions aimed at satisfying multiple goals in environments that are not perfectly predictable.

In this study emotions constituted the primary motivational systems of humans and each of the primary emotions like joy, anger, distress, disgust, and shame supplied its own unique kind of motivating information. The emotions are normal and should become less severe and less

frequent as time passes. Schoefer and Ennew (2005:4) add that emotions are complex and arise from many sources.

Ross (1997:1) refers to emotions as “subjective feelings that are essentially private experiences”. These emotions and related experiential states may be inferred through observable or quantifiable behaviours called indicators. However, there is no consensus on whether or not a particular indicator or class of indicators is either necessary or sufficient for emotional experiences. Ross (1997:6) supports Darwin’s view of certain emotions as primary emotions that have as their substrate innate neural bases since they are universally expressed and understood across cultures. The experiential aspects of primary emotions include fear, panic, sadness, surprise, anger, joy and disgust.

2.3 EMOTIONAL EXPERIENCES AND VISION LOSS

Emotions are an essential part of how people experience the world (Huang & Alessi 2003:1).

Although each person’s reaction to the diagnosis of serious, irreversible vision loss is different, for many people this is devastating (Community Services for the Blind and Partially Sighted [CSBPS] 1996:1). When a person learns that it is necessary to have an eye removed, the news creates concern and apprehension. Mostly, the patient feels alone, convinced that the worst has happened, there is no hope of ever leading an active independent life again. Time is needed to adjust to how the situation will affect the person’s life, appearance and ability to function independently (Kolberg Ocular Prosthetics 2005:1).

According to Fitzgerald and Parkes (1998:1161), most blind people are not born blind but become blind from a variety of causes. This is referred to as acquired blindness. Having relied on their sight to recognise and relate to the world, they now have to radically revise their basic assumptions about the world. Acquired blindness is usually an overwhelming personal and family catastrophe affecting the patient’s mobility, appearance, work, personal relationship and much more else.

People new to vision loss have to deal with the impact of diagnosis, learn about their eye condition, understand its functional implications, reconsider self-concepts, address issues related to family and friends, think about a host of practical issues and cope with a wide variety of emotions (Fitzgerald & Parkes 1998:1161).

Hupfeld (1999:1) maintains that the factors affecting response to visual loss are not necessarily related to the level of sight loss. Much depends on individuals' social situations, personality and coping abilities. For older people especially, other health and age-related problems affect how they cope with activities for daily living. Allen (1989: 640) adds that the feeling and response at the time of the loss is related to subjective interpretation of the experience, and, although each individual's response to visual loss is unique, there are meanings that are shared by people in similar situations.

Tolley and Henninger (1991:18) found that most patients, especially those blind from enucleation, experience some difficulty with altered function for some time. A few lost their "better eye" as a result of trauma and were faced with drastic changes in their lifestyle after enucleation. Some could no longer drive or resume their job prior to enucleation or evisceration, causing significant stress and at times financial problems. Others found that they could not rely on family members for support due to the family members' own feelings about the loss of the eye. Morrison-Fokken (2003:1) states that sight loss is a traumatic experience that affects almost every aspect of a person's life. It can be sudden or expected, but individuals are unique in how they experience this event. Sight loss can impact on the patient's relationship, job, hobbies, confidence and independence. Some people fear that they have lost their future, sense of identity, even their role in life. Madu (2004:112) reports a correlation between vision loss and depression. Many people who lose their eyesight become depressed and 50% experience some type of depressive effects four years after visual loss.

Emotional trauma can result from common occurrences, bereavement, humiliating and deeply disappointing experiences, life-threatening or disabling conditions. Jaffe, Segal, and Dumke (2005:1) emphasise that traumatising events can take a serious emotional toll on those involved, whether that event did or did not cause a physical damage. In the patient's mind it "was unexpected, the patient was unprepared and there was nothing the person could do to prevent it from happening" (Jaffe et al 2005:1).

Ignatavicius and Bayne (1991:200) state that facing the pain and living through its full range of feelings and their expression achieves effective grieving. Patients' emotional reactions resemble those experienced with other significant losses in life and probably even the ways of coping with grief and rejoining the mainstream of life are similar. Therefore, experiencing and accepting all feelings remains an important part of the healing process.

McBride (2005:36-37) adds that sight loss is often linked to bereavement and as with any major loss in life people need to grieve before they can move on. Also, the family and friends need to adjust to what this means for them as well as for the visually impaired person. Therefore, grieving is said to be a natural response to significant and presumably emotional aspects of visual loss (Hospice Net 1996:1).

According to the CSBPS (1996:1), grief is painful and at times the pain seems unbearable. Grief is a combination of many emotions that come and go, sometimes without warning. It is the reaction to the loss of someone or something that really matters both personally and emotionally, and no one is immune to the experience of loss. Realising that one will be facing the future with partial vision can come as a shock. Whether vision loss is gradual or sudden; people experience a sense of shock or disbelief (Sight Care 2005:1).

2.4 STAGES OF BEREAVEMENT AND VISION LOSS

Losing an eye through enucleation or evisceration is a traumatic and distressing experience, following which grieving needs to occur. Loss of vision, complete or partial, can be similar to the “loss of a loved one”. The grieving process that applies in death also applies to the loss of an eye or sight (AMD Alliance International 1999-2005:1). Understanding, sensitivity and support of family, friends and helping professionals, especially nurses can go a long way towards assisting patients with vision loss to find their own best way of coping with this new reality.

Preconceived ideas of blindness and handicapping conditions in general play a significant role in patients’ reaction to the news that they have lost an eye and/or sight. The negative images can lead patients to ignore any remaining vision and continuing potential independence (See no evil, hear no evil) (Sight Care 2005:1). A range of emotions and behaviour may accompany vision loss and individuals react differently to losing vision. In addition, emotions can surface at different times and recur in cycles.

2.4.1 Shock or disbelief and denial

Cruse (1999:3) points out that the initial reaction to loss of sight is often one of shock and denial and these reactions may be experienced in different ways. At this stage individuals have not fully comprehended or been able to integrate the depth of change in their life. This stage may last for brief or extended periods. Read (2002:47) maintains that loss is an integral part of human

experience. Penson (1992) cited in Read (2002:47) is of the opinion that the concept of loss is the key to the true understanding of bereavement. Immediately a person learns about a significant loss, a feeling of disbelief sets in. There is emptiness and numbness. According to Hospice Net (1996:1), most often people feel several of these emotions at the same time, perhaps in different degrees. People do not want to believe that this is happening to them. This denial functions as a defence mechanism to protect them against the pain of the unexpected, and thus does not allow them into consciousness. Kubler-Ross and Kessler (2005:10) maintain that shock and denial help people to cope and make survival possible. Denial helps people to pace their feelings of grief.

2.4.2 Emotional expression or anger

Anger can manifest in different ways; and it is an attempt to avoid the true underlying cause of visual loss and sight. People dealing with emotional upset can be angry with themselves, and/or with others especially those close to them and may feel anger at the unfairness of life (Chapman 2006:4). At this stage the patient realises the full impact of the loss, and may express emotions through tears, sadness or anger. Hospice Net (1996:1) posits that people of faith may be angry at God for allowing so much pain and anguish. In this case denial is replaced by the feeling of resentment, envy, anger and rage, and questions such as “Why me?” “Who is at fault?” are common. The anger comes from a sense of frustration that there is nothing that the patient, doctors and family can do to prevent vision loss (CSBPS 1996:1-2).

Furthermore, when patients move out of depression, they often have more energy. Therefore, expressing anger helps them to begin to direct the grief outwards and allows them to move beyond the feeling that “life is not fair” (CSBPS 1996:2-4). Kubler-Ross and Kessler (2005:11) add that it is important to remember that anger surfaces once people feel safe enough to know that they will probably survive whatever comes. Therefore, anger is declared a necessary stage of the healing process.

2.4.3 Guilt

The next reaction is guilt. Patients feel guilty about things they have not done to save their eye. Usually patients blame themselves, health professionals, and significant others for something that was neglected around the time of the loss. These feelings are often attempts to understand why the loss has occurred. In most cases guilt is normal, though not justified (CSBPS 1996:2).

2.4.4 Bargaining

Bargaining is a vain expression of hope that the bad news is reversible. The normal reaction to feelings of helplessness and vulnerability is often a need to regain control. Reaching the bargaining stage shows that individuals have begun to face the fact that they have lost sight/vision. They are past the denial stage. This stage helps individuals look at what caused the problem in the first place (Nix 2006:2). Kubler-Ross and Kessler (2005:20) add that as people move through the bargaining process, the mind alters past events while exploring all those “what if” and “if only” statements. Sadly, the mind inevitably comes to the same conclusion: “the tragic reality is that my eye is gone, I will never see the light again”.

2.4.5 Depression and isolation

Kubler-Ross and Kessler (2005:20) emphasise that after bargaining people’s attention moves squarely into the present. Empty feelings present themselves, and grief enters their lives on a deeper level, deeper than they ever imagined. However, Nix (2006:14) maintains that depression is normal and it may last longer in some people than in others. This stage is associated with feelings of depression, guilt and unfamiliarity. Rage exhausts itself; the permanence of loss begins to be recognised more realistically, and most patients start to feel dispirited and experience a sense of great loss (Ignatavicius & Bayne 1991:2001). Therefore, when patients realise that the loss is real and unchanging, they may sink into deep sorrow, feel very alone, and fail to believe that no one else can understand the full impact of their loss. Patients may then resort to withdrawal, especially from social life. They feel helpless and hopeless and believe that they have no reason to live. The realisation that an individual will never see again, that the loss is final and irrevocable, strikes like lightning. The high risk of depression is seen in those patients who have other health problems and/or lack social support (Callahan, Jaffe, Segal & Segal 2005:6; CSBPS 1996:2).

2.4.6 Acceptance

According to Kubler-Ross and Kessler (2005:25), acceptance is where people’s final healing and adjustment can take a firm hold, despite the fact that healing often looks and feels like an unattainable state. Patients may resist returning to normal activities. These attempts are painful and stressful, especially if new skills have to be learned or rather significant life changes made (CSBPS 1996:2). As time passes, patients experience periods of hope that things will improve

and the future holds promises. This is accompanied by the realisation of new skills that enable them to return to normal and undertake significant activities. It usually takes a long time for patients to reach this stage and the time varies with individual patients (CSBPS 1996:2).

Finally, patients realise their potential to live and have an active role in life. By this time they have adjusted to the new reality that has been created by their loss of sight. For some, it may take weeks or a few months to bring a sense of peace and renewed hope, while others may experience desperation of varying frequency and intensity for many years. What works for one may not necessarily work for the other (CSBPS 1996:3). Therefore, it is important to remember that one of the most difficult aspects of vision loss is the mental and emotional turmoil people go through when they find out that they will lose or have lost sight.

2.5 CAUSES OF EMOTIONAL AND PSYCHOLOGICAL REACTION TO BLINDNESS OR LOSS OF AN EYE

In a literature review on the impact of society or a combination of societal and personal factors rather than the sole personal experience on blindness or sight loss, Hudson (1994:498) found the emotional and psychological reaction to blindness or loss of sight an important issue because it affects the services that rehabilitation agencies offer to people who are blind or have lost sight. Hudson (1994:498) maintains, however, that if reactions to blindness or loss of sight are inherent in the experience itself, then the role of counsellors, instructors and administrators of rehabilitation agencies is to assist individuals adjust to vision loss or blindness through conventional methods. Furthermore, if there is a social component to these individuals' reactions, then the role of the professionals in the field should be wider and more varied. The causes of reaction to blindness or loss of sight are frequently described as social, personal and/or a combination of the two.

2.5.1 Social situations

The first thing to consider is the source of emotional and psychological support of persons with impaired vision in relation to their environment (Hudson 1994:498). Cutsforth (1951:122) (cited in Hudson 1994:498) holds that blind or partially sighted people do not experience any emotional difficulty until they are involved in social situations where the attitudes of the sighted are viewed as responsible for the emotional disturbances.

Chevigny and Braverman (1950:34) (cited in Hudson 1994:498-499) state that every blind or partially sighted person reacts to the environment either consciously or unconsciously. They add that resentment is a primary emotional reaction to blindness or loss of vision. This emerges from a series of social situations that first arouse anger.

According to Jerigan (1965) and Scott (1969) (cited in Hudson 1994:499), the main issue is the “lack of understanding and misconceptions of blindness and not the experience of the loss of vision, and the need to acquire new skills and techniques”. These authors go on to say that it is impossible for blind people to ignore the beliefs imposed on them, and this results in feelings of shame and inadequacy.

2.5.2 Personal situations

Hudson (1994:500) found that impaired vision caused consequent emotional and psychological reaction. To this effect, Cholden (1958) cited in Hudson (1994:500) notes that common reactions to losing sight or becoming blind include shock, depression, grief and resentment. In addition, there was a belief that blindness represents “death”; that is, a blind person “must die as a sighted person and be reborn as a blind person” (Hudson 1994:500). In that case a person learns to live all over again in a new kind of world with a new set of sensory instruments. In this way the patient mourns the loss of the sighted self. These reactions to vision loss are viewed as stemming from factors inherent in individuals’ personalities and experiences. They vary according to the degree of vision loss, age of onset, social and emotional support available and individual coping strategies.

2.5.3 Combinational situations

Societal and personal causes are often combined. According to Hudson (1994:500), reactions to vision loss stem from the person’s attitudes and those of others like family members and/or friends as well as age at onset of vision loss. These reactions are determined by personal traits, social circumstances and physical facts of vision loss, attributable not to the quality of the loss itself, but to special problems that come from it and the meaning the loss has for an individual.

2.6 CONSEQUENCES OF REMOVAL OF AN EYE

The Royal Institute of the Blind (1995-2006:2) emphasises that losing sight/vision through enucleation or evisceration can be difficult to cope with, as it can affect so many different aspects of a person's life. Although people react differently to things that happen to them in life, there are some feelings that many people who have lost their sight/vision often describe. These include feeling depressed or angry; feeling a drop in confidence when every task becomes a challenge, and finding themselves becoming withdrawn and wanting to avoid people.

2.6.1 Facial appearance and the emotions thereof

Something that is not often considered in the planning phase of enucleation/evisceration, but which becomes an important factor after surgery, is the person's appearance postoperatively; the ocular prosthesis; its colour and size and the person's feelings about the prosthesis (Kolberg Ocular Prosthetics 2005:1).

When one loses an eye or the appearance of the eye is altered by accident, disease or surgery it is not surprising that the patients are just concerned about their facial features. Health providers are often flooded with questions like "What happens if my eye looks different? Will people ask me about it? Should I mention it myself? What will I say if someone asks what happened to my eye?" According to Hehir (2000:8), this concern only highlights the psychological aspect of disfigurement as one of the main concerns patients have following removal of an eye.

Tolley and Henninger (1991:18) identify body image disturbances as one of the stressors following the removal of an eye. In their study they found that patients, whether elderly or young, male or female, were very concerned about physical appearance. They wanted realistic information about cosmetic results and wanted opportunities for plastic procedures to improve the fit and the appearance of an artificial eye (prosthesis).

Migliori (1999:99) and Hehir (2000:8) found that often patients are not emotionally prepared to cope with the cosmetic changes that follow the loss of an eye, especially through enucleation. A sense of isolation can develop from the perceived disfigurement of the face. Left unaddressed, this isolation can lead to poor psychological and functional recovery. Piff (1998:13) points out that initial face-to-face encounters demand eye contact to make immediate judgements. Eye contact conveys non-verbal communication cues.

Beed (1991:27) found that one patient saw enucleation as a final and irreversible step. As body image is important to everyone, the patient was worried about appearance after surgery, imagining gaping orifices where the eyes had been. Although the patient was normally a calm person who coped well with disability, in this instance she was frightened and expressed anxiety about how her children, husband and the rest of the family and friends would react to her appearance.

2.6.2 Quality of life

Vader (1992:705) emphasises that the incredible role that vision plays in everyday life is often never fully appreciated until it is compromised or lost. The extent to which a person can independently perform the activities of daily living is, for the most part, related to an ability to interact with the environment.

While most people believe that they intellectually understand what it entails to lose sight, they may not really understand what this means to an individual on a daily basis. Research has not quantified the impact loss of sight has on quality of life, except to refer to compromise thereof.

2.7 SURGICAL APPROACHES

Removal of an eye whether because of disease or trauma involves more than a surgical procedure. Migliori (1999:xiii) illustrates that it is not only necessary to select the best surgical procedure for the patient, but also to help the patient confront the loss and prepare for life with one or no eyes.

There are three techniques used to remove the eye, namely enucleation, evisceration and exenteration and each is performed for specific reasons. This study focused on two methods, enucleation and evisceration. Exenteration is only mentioned as it can be performed following enucleation in cases where cancer has spread to the orbital bones and the optic nerve.

2.7.1 Enucleation

Enucleation has been a standard procedure for treating certain cases of intraocular malignancy for more than one hundred years. Recently, however, with advances in technology enucleation is

performed only when the condition does not respond to other forms of treatment like proton beam irradiation (Migliori 1999:8; Petrowski 1986:135).

Enucleation is the removal of the entire globe with a small portion of the optic nerve while retaining the conjunctiva, bulbar fascia (to provide a lining for the socket) and extra-ocular muscles. These muscles can be placed around an orbital implant to provide for the movement of the prosthetic eye (Migliori 1999:8; Petrowski 1986:135; Sen 2005:1; Hehir 2000:8-9).

- **Indications for enucleation**

Moshfeghi, Moshfeghi and Finger (2000:278) state that whenever enucleation is recommended, ophthalmologists take into account the patient's psychological makeup, visual potential of the removed eye, the patient's cosmetic concerns and the potential complications.

According to Davies (1997:3), enucleation is indicated in

- intra-ocular tumour or malignancy such as retinoblastoma or choroidal melanoma whereby the globe and the intra-ocular contents are removed for pathologic study
- a blind, painful eye usually secondary to end-stage glaucoma, retinal detachment, chronic inflammation or trauma
- severe infections such as endophthalmitis or panophthalmitis

Migliori (1999:8) describes the indications of enucleation as

- a procedure of choice when histopathologic examination of the globe and optic nerve is required
- a diagnostic measure in intraneural or extrascleral extension of intraocular malignancy
- a traditionally preferred procedure in cases of extensive eye trauma, such as penetrating or perforating injuries to the uveal tract
- a means to decrease the risk or treat sympathetic ophthalmia. Enucleation of the affected eye is sometimes recommended within two weeks of the onset of sympathetic ophthalmia, particularly when combined with corticosteroids therapy. It offers the best visual prognosis for the sympathising eye
- a preferred procedure over evisceration when the patient has a small phthisical eye that does not tolerate a shell and when evisceration does not yield satisfactory cosmetic result

- a preferred procedure in childhood, in cases of a painful, blind eye with severe buphthalmos
- a preferred procedure over evisceration when the globe is severely deformed or disfigured in exophthalmos or buphthalmos
- **Disadvantages of enucleation**

According to Migliori (1999:9-10), the disadvantages and potential complications of enucleation are unique as an anophthalmos socket develops a decrease in orbital blood flow and pathophysiology becomes very different from the normal orbit. Enucleation can lead to fat atrophy or contraction and eyelid malpositions such as ptosis, entropion or ectropion may follow.

During childhood, enucleation may result in motility disturbance, impairment of bony growth and development of superior sulcus syndrome or socket contraction. Exophthalmos, enophthalmos and poor prosthetic mobility are also possible sequelae that may yield cosmetically unacceptable results (Migliori 1999:9-10).

2.7.2 Evisceration

Evisceration is the removal of the contents of the globe leaving the sclera intact. The optic nerve and the extra-ocular muscles remain attached to the sclera and as a result evisceration generally gives better movement to the ocular prosthesis (artificial eye) than enucleation (Sen 2005:1). Both Hehir (2000:8) and Migliori (1999: 6) describe evisceration as a surgical technique in which the entire intra-ocular contents are scooped out, leaving a scleral shell and the extra-ocular muscle attachments intact.

- **Indications for performing evisceration**

According to Migliori (1999:6), evisceration is usually performed for a blind eye with or without pain following trauma or infection (see figure 2.1).



Figure 2.1

Painful red eye with corneal ulcer and hypopyon (pus in the anterior chamber)

Source: <http://www.mrcophth.com/oculoplasticgallery/evisceration/evisceration.html>

- **Advantages of evisceration**

Evisceration as a procedure has recently gained popularity and acceptance. Dresner (2005:5) maintains that evisceration offers many advantages over enucleation including improved postoperative fornices and implant motility, easier prosthetic fitting, and generally improved cosmesis.

According to Migliori (1999:6), the advantage of evisceration is that only the globe is penetrated. The Tenon's capsule, optic nerve, orbital septum and remaining orbital contents are left undisturbed. In theory, the risk of meningitis from the spread of infectious organisms is decreased because the sub-arachnoid space is not penetrated during evisceration.

The procedure is easier to perform and is usually quicker and may be preferred in patients at significant risk from prolonged general anaesthesia (Migliori 1999:6). Evisceration yields better motility and cosmetic results than enucleation, particularly if the cornea is retained, due to less disturbance of normal orbital anatomy.

However, although leaving the cornea intact allows placement of a larger implant and lessens the likelihood of postoperative enophthalmos, Migliori (1999:106-107) contends that the main disadvantage to preserving the cornea is retention of the terminal branches of the trigeminal

nerve, which may lead to ocular pain that continues after surgery in many cases. This implant shown in figure 2.2 is inserted to maintain the volume of the orbital cavity.



Figure 2: Hydroxyapatite-based porous implants for evisceration surgery

Figure 2.2

Hydroxyapatite-based porous implants for evisceration surgery

Source: http://www.ijo.in/viewimage/asp?img=IndianJOphthalmol_2005_53_4_235_18904_7ipg

Another advantage of evisceration is the preservation of orbital volume. In evisceration there is less fat atrophy and disruption of the orbital contents. This preservation of the sclera and corneo-scleral layers provides an additional 0.5ml of volume, essential for the comfort of the patients as they can wear slightly smaller prostheses. This also preserves better motility because the extra-ocular muscles are not manipulated (Migliori 1999:107).

- **Contra-indications for evisceration**

Evisceration is not always indicated. Evisceration may be

- very difficult in a small phthisical eye because the sclera may be unable to support a proposed implant (Migliori 1999:108).
- technically difficult in cases of chronic inflammation because the eye may be soft, making it difficult to remove all the uveal tissue and to manipulate and suture the eye (Migliori 1999:108)

- contra-indicated when pathologic examination of the globe is required whereby there is a theoretical increased risk of sympathetic ophthalmia compared with enucleation (Sympathetic Ophthalmia is a bilateral granulomatous inflammation that may occur in two weeks or even years after trauma to the uvea of one eye and may threaten the vision of the uninjured eye)
- contra-indicated in cases of intra ocular malignancy (Migliori 1999:108)

2.7.3 Exenteration

According to Levin (1998) cited in Migliori (1999:139), exenteration is the removal of the entire eye and the orbital contents. Sen (2005:1) states that exenteration is a disfiguring procedure reserved mainly for control of aggressive malignancies like sebaceous cell carcinoma, melanoma or advanced squamous or basal cell carcinomas, retinoblastoma with orbital involvement.

Retinoblastoma is the most common childhood intra-ocular malignant neoplasm affecting 1:20,000 to 1:34,000 children. Although most retinoblastomas are unilateral, up to 25% of sporadic and most inherited cases are bilateral. However, the goals of treatment should be to improve the quality of life, retain the eye, preserve the vision and, where possible, facilitate good cosmetic results (Bernardino, Jefferson & Rubin 2002:1).

2.8 COMPLICATIONS OF ENUCLEATION AND EVISCERATION

2.8.1 Early complications

According to Migliori (1999:161) immediate complications include haemorrhage, infection and extrusion of the implant. The author reports that post-operative haemorrhage is mostly seen in patients who are either on blood thinners, like Aspirin, or are known to have a bleeding disorder. Orbital infections although rare, may occur with integrated implants. Extrusion of implants may be a result of orbital infection, haemorrhage, oedema, and poorly sized conformer (Migliori 1999:161). Most infections can be managed with antibiotics and implant extrusions managed surgically.

An extremely rare but most serious complication is removal of the wrong eye. Therefore strict pre-operative measures are required to avoid this possibility.

2.8.2 Late complications

A number of late complications may occur. According to Migliori (1999:161), late complications occur months to years after surgery. Moreover, early or late complications of enucleation or evisceration are directly related to the type of implant used.

Complications include extrusion, implant migration, orbital volume deficiencies, lid abnormalities and superior sulcus defects that result from inadequate orbital volume or downward displacement of orbital contents (Migliori (1999:163). Inadequate orbital volume can be caused by insufficient volume replacement at the time of surgery, or secondary to one of many possible mechanisms, including orbital fat atrophy and decreased blood flow to the socket.

According to Migliori (1999:164), other complications include:

- Scar formation which may occur and disturbance in the architecture of the orbit that can hamper the socket's ability to hold the prosthetic shell. In a small number of patients surgery may be required to correct this at a later date.
- Ptosis which frequently accompanies superior sulcus defect and may not be evident until the sulcus defect has been repaired. This condition can be repaired easily under local anaesthesia.
- Lower eyelid laxity that can be caused by the pull of gravity on the prosthesis and downward displacement of the orbital contents.
- Enophthalmos, which is associated with superior sulcus defects and lid laxity, due to the sinking of the fractured orbital floor precipitated by enucleation.
- Reduced growth of eye socket, when the eye is removed. In this instance the surrounding socket may fail to grow at the same rate as that of the healthy eye. This occurs mostly in children and young adults. In most cases, implantation of progressively larger prosthesis can be used to stimulate the bony growth.
- Children may develop a hypoplastic orbit.
- Sympathetic ophthalmia, which occurs very rarely in patients who have undergone evisceration, as the antigen that leads to sympathetic ophthalmia, cannot always be completely removed.
- Poor prosthetic motility, due to a poor technique in the fitting of the prosthesis

- Extrusion or loss of the orbital implant where the orbital implant may come out due to excessive scarring or infection. Surgical correction with replacement of the implant can be carried out when infection resolves.
- Migration of the implant, which can lead to poor cosmesis and decreased motility. This often occurs in the infero-temporal direction.
- Implant exposure and extrusion are two of the most serious complications that follow enucleation. Exposure of implant invariably leads to extrusion with loss thereof. This is common with hydroxyapatite orbital implants (Migliori 1999:164) (see Figures 2.3 and 2.4).

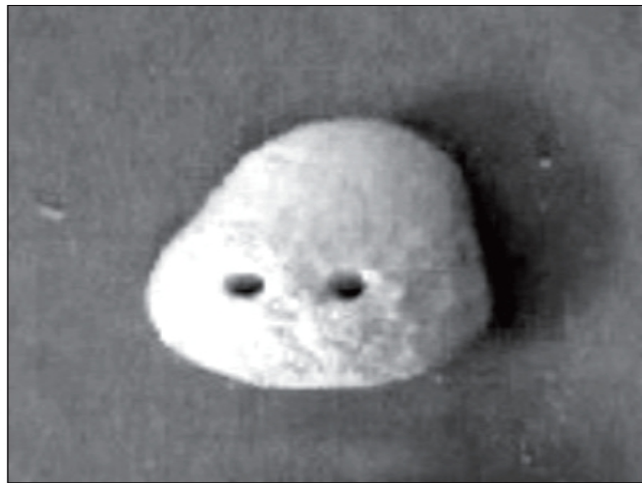


Figure 3: Hydroxyapatite-based porous implants for enucleation surgery

Figure 2.3

Hydroxyapatite-based porous implants for enucleation surgery

Source: http://www.ijo.in/viewimage.asp?image=indianJOphthalmolol_2005_53_4_235_18904_7.ipj



Figure 4: Anterior implant exposure of 3–4 mm, which however could be subsequently managed by patch grafting with donor sclera.

Figure 2.4

Anterior implant exposure of 3-4 mm, which however could be subsequ

Source: http://www.ijo.in/viewimage.asp?img=indianJophtalol_205_53_4_18904_9.jpg

2.9 PRE-OPERATIVE CARE FOR ENUCLEATION AND EVISCERATION

Sen (2005:1) states that pre-operative counselling is vital and should be tailored according to the patient's circumstances. Further, patient's needs, concerns and expectations must be addressed before any procedure is selected.

Sen (2005:1) adds that patients with a blind and painful eye, who request surgery, tend not to require as much counselling as those with a newly diagnosed intra-ocular malignancy. Migliori (1999:1) concurs, stating that patients with long-standing blindness or pain, severe deformity, or intra-ocular tumour may be more open to difficult procedures than ones with recent acute infection and trauma.

Smith (1997) cited in Migliori (1999:108) mentions that if surgery is indicated, many factors should be considered, such as emotional status, the general health of the patient, acceptance of the disease and the difficulty of the proposed procedure. In many instances, it is best that the patient be prepared over time for any of the eye procedures. Hehir (2000:19) points out that some patients will have the opportunity to plan for their admission and come to terms with the impending surgery while others, especially with malignant melanoma, trauma and severe infection, may be rushed in with very little time to prepare, particularly emotionally. Therefore good communication skills are necessary to allay anxiety and reduce stress with this type of hospitalisation. Hehir (2000:19) adds that multidisciplinary team effort with inputs from the

ophthalmologist, ophthalmologist, ophthalmic nurse counsellor, ophthalmic nurse and other professionals is required prior to surgery to build good interpersonal relationships.

In many instances patients express concern that the wrong eye may be removed. Therefore the ophthalmologist needs to obtain informed consent from the patient, and mark the area above the eyebrow of the eye to be operated with indelible ink. The nurse who carries out the pre-operative preparation must ensure that the eye to be operated upon is correctly identified. The checks continue in theatre while the patient is on the operating table (Hehir 2000:19).

Besides physical care, psychological and emotional care are usually a concern as fear of disfigurement and pain feature high on patients' needs. Sen (2005:1) found that many patients' anxieties might be allayed by explaining what to expect during their stay in hospital; the functioning in the remaining eye; how much pain to expect; how to overcome such pain; what the socket will look like; the state of an artificial eye and its appearance; whether there will be some degree of movement or not, and how soon the artificial eye will be available.

Another important issue in preparing patients for surgery is the involvement of the nurse, as the nurse will follow the patients throughout their stay in hospital and continue to liaise with them as long as is necessary. The nurse must therefore familiarise herself with basic counselling skills and be able to recognise when the need arises for more in-depth counselling or psychological care. The ophthalmic nurse's role is to link the patient with local support services that are available and make the necessary contacts with these before the patient is discharged in order to ensure continuity of care after discharge (Hehir 2000:10). Individual assessment of patients' needs in respect to self-care skills and motivation is an important aspect of pre-operative care. Permission from the patient to include a family member should also be considered, as this is important in facilitating acceptance in altered body image.

Finally, patients' wishes should be respected especially those who desire not to discuss the operation or the aftercare until the operation is over. In such cases, it is important to bear in mind that the grieving process may be prolonged (Hehir 2000:10).

2.9.1 An artificial eye (ocular prosthesis)

An ocular prosthesis or artificial eye replaces a missing natural eye following enucleation or evisceration. The ocular prosthesis typically takes the shape of a convex shell. Most ocular prostheses are made of kryolite glass or medical grade acrylic (see Figure 2.5). Physical care of the socket as well as removal and insertion of the prosthesis need to be discussed and addressed with the patient pre-operatively.

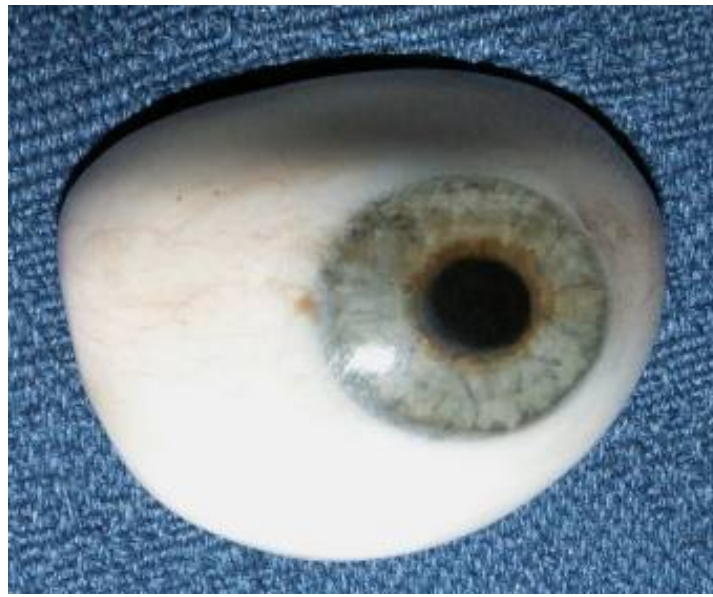


Figure 2.5

A Prosthesis right eye, made from Acrylic

Source: http://en.wikipedia.org/wiki/Ocular_prosthetics

2.10 POST-OPERATIVE MANAGEMENT FOLLOWING ENUCLEATION AND EVISCKERATION

2.10.1 Immediate care

At the completion of enucleation or evisceration a pressure patch is applied over the eyelids. The patch is intended to keep the swelling of the socket tissue to a minimum and to prevent haemorrhage. The patch is kept *in situ* for one to four days, depending on the surgeon's preference and the condition of the patient at the time (Wills Eye 2004-2005:1). During this period the patient commonly experiences some difficulty opening the eyelids of the un-operated eye. This can be quite frightening to the patient in this situation. At this time the patient needs to be reassured as the difficulty in opening the eyelids generally resolves itself after the first post-

operative day or soon after. The patient is also advised to avoid excessive movement of the head (Wills Eye 2004-2005:1-2).

Nausea and vomiting may be observed in some patients. Measures to overcome this feeling should be taken and the patient's comfort maintained at all cost.

In general, moderate post-enucleation pain in the socket occurs during the first twenty-four (24) hours. Pain relievers are usually prescribed as needed to reduce discomfort. A small amount of bruising, swelling and some numbness of the surrounding tissue are normal and to be expected. The patient must be made aware of this and cold compresses be commenced to reduce swelling quicker (Wills Eye 2004-2005:2). Usually a patient is prescribed a course of oral antibiotics to prevent infection and oral steroids to reduce inflammation for seven days or longer.

The length of hospital stay varies and depends on the type of surgery. The average stay is twenty-four to thirty-six (24-36) hours for evisceration and forty-eight to seventy-two (48-72) hours for enucleation. All these depend on the surgeon and the condition of the patient at the time. In some instances, the patient may have been fitted with a conformer in front of the implant to maintain the normal shape of the socket while it is healing. Therefore there will also be a small amount of pinkish discharge for the first three to four days, which will diminish with time.

Firstly, an outpatient appointment is arranged after seven to ten days, for the surgeon to check the condition of the socket. Then after four to six (4-6) weeks to again check the socket and arrange for the temporary prosthesis to be fitted (see Figure 2.5). An impression of the socket is taken and the affected eye is reconstructed to match the existing eye (see Figure 2.6).



Figure 8: Status of the socket and fornices postoperatively taken 3 weeks after surgery

Figure 2.6

Status of socket and fornices, three weeks after surgery

Source: <http://www.ijo.in/viewimage.asp?img=IndianJOphthalmol> 2005

2.10.2 Health education

The patient is taught how to remove, clean and replace the shell (conformer) as well as clean and instil the prescribed drops or ointment. A small dressing may be applied to the wound. Some patients prefer to wear dark glasses or cartella shields post-operatively over the socket.

The patient is advised to observe for signs of infection, pain, bleeding and how to access medical and psychological support if required. The patient needs to be advised of the changes in the stereoscopic vision, altered depth/distance and field of vision. Therefore, extra care should be taken when using steps, judging distance and looking towards the affected side (Migliori 1999:100). To gain a wider field of vision patients are advised to turn the head slowly in the desired direction. Patients should be reassured that the skills of depth perception can be relearned with time.

Usually patients will ask if they should remove the ocular prosthesis (artificial eye) at night. This is not recommended as it may contribute to shrinkage and deformity of the socket. Ongoing care of the prosthesis is recommended. Protecting the remaining eye is important especially if the patient takes part in sports. Advise on wearing safety glasses outdoors and indoors (Migliori 1999:102). Advise regular visits at least every six months to a qualified ophthalmologist (Lost Eye 2000-2005:1).

In addition, the patient should be advised to avoid any surgical procedures such as corrective surgery that have the risk of introducing disease or abnormalities into the good eye. Safety concerns and precautions must be addressed to protect the remaining good eye in individuals with monocular vision. Involvement of the carer, partner or family member is encouraged unless the patient objects. This is done to ensure that help and support are available after discharge and acceptance of the altered body image is facilitated (Politzer 2001-2004:6).

2.11 THE IMPACT OF LOSS OF VISION ON THE PATIENT

According to Madu (2004:110-111), loss of vision through diseases or trauma causes major changes in the quality of life. Not only is a person no longer able to perform all the usual tasks and activities to the same extent as previously, but changes in lifestyle, habits and roles may also result in a serious psychological adjustment. Individuals' social interaction is affected. Personal space preferences, distance between the visually impaired and others during social interaction are affected (Madu 2004:111). Patients may decide not to attend social engagements, as they may be acutely aware of their changed circumstances. Madu (2004:112) points out that loss of vision eventually results in loss of work, low job satisfaction leading to low productivity and eventual resignation or dismissal from work. Also, loss of vision is correlated to depression. The effect of the loss of the eye depends on a person's age, sex, family support and reason for the loss of the eye.

2.12 COPING WITH VISION LOSS

Loss of sight is among the most traumatic events that a person can experience. Anyone can experience grief and loss. It can be sudden or expected; however, individuals are unique in how they experience or respond to this event. Individuals respond to loss in various ways. Coping usually involves dealing with a grief reaction that can be slow and painful, and varies from individual to individual (Cass Grief and Loss 2004: 1). According to Morris (1991:26), some people lose an eye to an accident and have no choice but to have the eye removed immediately. Others start off with an eye that seems perfectly healthy, but because of cancer or other eye diseases the eye is removed to protect the rest of the body.

The Canadian Institute for the Blind (1996-2005) indicates that not everyone copes in the same manner with blindness or loss of vision. Individuals have unique experiences throughout life and will interpret and understand the changing world in their own way. Most people have always met

the challenges of life and are likely to continue to do so, whilst others, who may have been defeated by life's challenges, may succumb to depression, despair and isolation.

Acquired vision loss explores the long established and comfortable relationship individuals have with their body. Therefore, when vision loss is associated with normal physiological changes, it changes people's perception of themselves.

2.12.1 Young age

Morris (1991:26) holds that children who lose one or both eyes do not usually have the same feelings of bereavement as adults, and may adapt quite quickly. But parents may need a great deal of support, especially if the child was injured and parents feel responsible or even guilty that the child's eye consequently had to be removed. However, for the child to be able to cope in life ahead, the child needs to be presented with ocular prosthesis options. Children have a very vivid memory or imagination, and if told half-truths will imagine the worst and feel betrayed.

Therefore in order to get the information across, simple explanations and pictures are appropriate and children develop a better attitude towards ocular prosthesis provided they have good vision in the remaining eye.

2.12.2 Teenagers and young adults

This group is mostly concerned about the body image and need a lot of counselling and support. These patients might have lost an eye through trauma, and may be suffering from shock and the decision to remove the eye would have been made rapidly with no time to assimilate the information (Morris 1991:26).

Basically, teenagers are just beginning to appreciate their appearance, especially their attraction to the opposite sex. Therefore, the idea of having an eye removed is terrifying and mutilating. They would prefer to have someone of their own age, who has undergone a similar operation, talk to them and answer their questions, give advice about make-up, boy/girlfriends and allay their anxieties and fears (Morris 1991:26).

2.12.3 Adults

Morris (1991:26) indicates that adults who are already married with families will worry about the effect on their partners and families. Therefore, it is advisable to involve the whole family in the counselling sessions where their fears can be dealt with, talked through and their questions answered. Arranging for a visit from an ex-patient can dispel their fears and myths.

Fitzgerald and Parkes (1998:4) emphasise that the family also needs an opportunity to share their grief as the impact of the patient's condition on their own lives becomes apparent. They need to be involved in the rehabilitation process from the start, so that they can become part of the rehabilitation team as well as recipients of its care.

2.12.4 The elderly

These patients would have had chronic infections or chronic diseases and severe pain. Therefore, in removing the eye, they may experience a drastic reduction of pain; so their reaction may be different. These patients may still grieve the same way as others, but the grieving process may be delayed or shorter. It is important not to underestimate their sense of loss (Morris 1991:26).

2.13 EMOTIONAL SUPPORT AND COUNSELLING OF PATIENTS WHO HAVE LOST AN EYE

McBride (2005:1) maintains that emotional support is everything people do when they are there for someone who is going through a hard time. Usually providing support entails time and attentive listening, non-judgemental and occasionally constructive suggestions. Also, it entails the situation where patients are allowed to articulate their feelings and are not considered weak, silly or inadequate. They are allowed space to work out their own solutions. McBride (2005:4) points out that counselling provides a non-judgemental, confidential setting that allows patients/clients to gain perspective and a better understanding of their situation and to develop more effective ways of dealing with potential problems.

According to Blaylock, Johnston and Hughes (2005:2), patients experience definitive stages of grief after loss of an eye including denial, awareness, anger and acceptance. These emotions may be delayed if there is immediate symptomatic relief after removal of an eye. However, the patient is likely to grieve at some point. Furthermore, the family members may have their own feelings

concerning the loss of an eye, and in some cases this interferes with their ability to show adequate support for the patient. Involving the family members in the patient's recovery enables the patient to cope better with the loss. Blaylock et al (2005:3) emphasise that patients experience depression after enucleation or evisceration, therefore professional nurses need to be prepared for these symptoms and should treat or refer patients to appropriate specialists in time.

2.14 ROLE OF THE OPHTHALMIC NURSE IN HELPING PATIENTS TO ADAPT TO VISION LOSS

Oehler (1982:28) maintains that the ophthalmic nurse can have a vital impact on the adjustment of patients to visual loss. Four factors impact on the role of the nurse, namely the nurse's knowledge of the adjustment process to visual loss; knowledge about communication of diagnosis and prognosis; attitude towards blindness, and knowledge of services that can be provided.

2.14.1 Knowledge of the adjustment process to visual loss

According to Oehler (1982:28), the patient with visual loss goes through the grieving process stages that may overlap and be individually more or less prominent. The family likewise mourns the loved one's visual loss. Therefore the nurse can assist the patient and the family to grieve by being supportive of their expressive feelings. Denial is healthy and serves as a protective function. The patient's denial should not be confronted. The nurse's knowledge and expertise are required.

Vader (1992:713) states that nurses and other health professionals can provide supportive and effective care to people, who must adapt to blindness or visual impairment, provided they are knowledgeable about the unique effect of ophthalmic disorders on body, spirit and mind. Furthermore, nurses must clearly understand their own emotions and social reactions to blindness and visual loss so that they can assist the patients through adaptation.

2.14.2 Communication of diagnosis and the prognosis

While it is the ophthalmologist's responsibility to inform the patient about the diagnosis and prognosis, the ophthalmic nurse can assist with the patient's adjustment to the diagnosis and

prognosis by patient teaching, providing support, and providing feedback to the ophthalmologist on the patient's and family's reaction to the diagnosis and prognosis (Oehler 1982:30).

The nurse who is familiar with issues surrounding diagnosis and prognosis will be in a better position to intervene on behalf of the patient. The nurse's role includes reinforcement of patient instructions often provided by the ophthalmologist. Should the patient be unclear about issues of diagnosis and prognosis the nurse can clarify these. She can develop instruction material including pamphlets, audio and video cassettes (Oehler 1982:30). The nurse can provide emotional support to help the patient and the family cope with fear.

2.14.3 Nurses' attitudes towards blindness

It is important for the ophthalmic nurse to convey a positive attitude towards blindness at the outset, since she is to provide the patient with information on how blindness affects people and how people react to blindness. A positive attitude will benefit the patient's self- and body image. Therefore the ophthalmic nurse should come to terms with her feelings about blindness and attempt to work through any negative reactions to blindness (Oehler 1982:31).

2.14.4 Services that can be provided to patients

Oehler (1982:31) points out that psychiatrists, psychologists, psychiatric nurses and social workers are not usually employed in an ophthalmic setting. It is advisable that the ophthalmic nurse take the responsibility to ensure that patients who lose vision are provided with resources to aid adjustment and rehabilitation. The nurse can be a liaison person between the ophthalmologist and the visual loss agencies. She also has the opportunity to work with the patient throughout the recovery and adjustment period.

Finally, Oehler (1982:32) emphasises the importance of the ophthalmic nurse's role as it can have an impact on patients' adjustment to vision loss. Nevertheless, little has been published on how the nurses should act and react therefore more research is needed to explore their role, especially on providing emotional support.

2.15 CONCLUSION

This chapter defined emotions and discussed patients' emotional experiences in order to understand their feelings following the removal of an eye; the surgical approaches (enucleation or evisceration); the indications, advantages, disadvantages, complications, pre- and post-operative management; patients' coping mechanisms, and the nurse's role in caring for these patients.

Chapter 3 describes the research design and methodology.

CHAPTER 3

Research design and methodology

3.1 INTRODUCTION

This chapter discusses the research design and research methodology which includes the setting, research population, sample and sampling technique, data collection and analysis, and ethical considerations.

3.2 RESEARCH DESIGN

Research design refers to the plan and overall structure of the investigation used to obtain evidence to answer research question. Parahoo (1997:142) defines a research design as “a plan that describes how, when and where data are to be collected and analysed”, while Burns and Grove (2003:195) describe it as “a blueprint for conducting a study with maximum control over factors that may interfere with the validity of the findings”. Polit et al (2001:167) describe a research design as the researcher’s “overall tool for answering the research question or testing the research hypothesis”. This study is qualitative in nature. It was based on a phenomenological research design that was non-experimental, contextual, exploratory, and descriptive in nature. The rationale for using this design was to explore and describe the emotional experiences of patients following the removal of an eye through enucleation or evisceration with the aim of gaining insight into the respondents’ feelings, experiences and perceptions of the phenomenon.

The design of this study is qualitative, exploratory, descriptive and contextual in nature. It is qualitative, as the aim is to conduct an in-depth study into the emotional experiences of patients who have undergone removal of an eye through enucleation or evisceration.

- It is exploratory, as it is aimed at exploring the patients’ emotional experiences following the loss of an eye.
- It is descriptive, as the researcher could observe and translate in understandable language the observed behaviour and verbalized emotions and feelings of patients following the loss of an eye through enucleation or evisceration.
- It is contextual, as the study was conducted in an eye hospital, and includes patients who

were operated at the hospital between the period 2000 and 2005.

Individuals who had undergone removal of an eye were interviewed in order to obtain descriptions of their lived experiences.

- **Qualitative research**

Burns and Grove (2007:61) describe qualitative research as “a systematic subjective approach used to describe life experiences and situations to give them meaning”. Parahoo (1997:59) adds that qualitative research focuses on the experiences of people as well as stressing the uniqueness of individuals.

Mathie and Camozzi (2005:17) emphasise that qualitative research is a particular approach to inquiry based on a particular set of assumptions about how knowledge is produced about the nature of reality itself. Brink and Wood (1998:246) and Burns and Grove (2003:374), further outline qualitative research as:

- a means to understand human emotions such as pain, anger, shock, joy, despair and distress
- a more effective method of investigating emotional responses since human emotions are difficult to quantify
- an approach that focuses on understanding the whole which is consistent with the philosophy of nursing
- a strategy that allows the researcher to interact with the participants, in that the researcher can ask questions based on previous responses. Thus, allows for in-depth probing of issues and yields great detail in response
- a paradigm through which thinking processes are used to develop research findings from which meaning and theoretical implications emerge

The description presented here above applies to the study undertaken. In this study the researcher focused on the feelings, emotions and experiences of the participants who had lost an eye by enucleation or evisceration.

- **Contextual research**

Mouton (1998:133) states that in contextual research strategy, the phenomenon is studied for its intrinsic and immediate contextual significance. Burns and Grove (2003:320) point out that contextual studies focus on specific events in their “naturalistic settings”. This study was done in the Coneo-Plastic Unit where the participants attended their follow-up clinic and had been in-patients for the operation.

- **Exploratory research**

Polit and Hungler (2003:19) state that exploratory studies are undertaken when a new area is investigated or when little is known about an area of interest. Burns and Grove (2003:313) add that exploratory research is conducted “to gain new insights, discover new ideas and/or increase knowledge of a phenomenon”. It is used to investigate the full nature of a phenomenon and other related factors as well as the manner in which it is manifested (Polit and Beck (2004:20). In this study an exploratory and qualitative approach was used to explore the patients’ perceptions and experiences following removal of an eye through enucleation or evisceration.

- **Descriptive research**

Burns and Grove (2003:201) state that descriptive research “is designed to provide a picture of a situation as it naturally happens”. The authors add that descriptive studies are the means of discovering new meanings when little is known about a phenomenon.

In this study, “descriptive” refers to the experiential meaning of the participants’ emotions following the removal of an eye. This method enabled the researcher to obtain a clear description of the phenomenon.

3.3 RESEARCH METHODOLOGY

Polit and Hungler (2003:233) refer to methodology as “ways of obtaining, organizing and analysing data”. Mouton and Marais (1996:16) state that research methodology focuses on the manner in which the research is planned, structured and executed in order to comply with scientific criteria. Therefore, research methodology assists in explaining the nature of the data, and highlights the methods employed that lead to the generation of appropriate conclusions

through applicable data processing. The main focus of this study was to explore and describe the emotional experiences of patients following the removal of an eye.

3.3.1 Research setting

In qualitative research, the context is significant as the descriptions of phenomena relate to the environment in which the study takes place as well as the culture of the participants thereof. The researcher must be sensitive to the context of the research, as this will enhance the understanding of the participants' point of departure.

The study was conducted at the Queen Victoria Hospital in the Corneo-Plastic Unit. Tables 3.1 and 3.2 represent the establishment of personnel in the unit.

Table 3.1 Number of nursing staff in the Corneo-Plastic Unit, 2006

NURSING STAFF	No
Unit Manager	1
Charge Nurse	1
Registered Ophthalmic Nurses	5
Registered Nurses	8
Enrolled Nurse	1
Ophthalmic Assistants	6
TOTAL	24

Table 3.2 Number of medical staff in the Corneo-Plastic Unit, 2006

MEDICAL STAFF	No
Corneo-Plastic Consultant	1
Oculo-Plastic Consultant	1
Oculo-Plastic Specialist	1
Corneo-Plastic Fellows	2
Oculo-Plastic Fellow	1
TOTAL	6

The Corneo-Plastic Unit is a referral and teaching unit. The attendance register shows an average of seven hundred and forty-four (n744) patients seen every month in the clinic from Monday to Friday, all with different eye problems. According to the attendance register, an average of seven

hundred and seventy-seven (n777) cataract extractions are performed yearly on day patients only.

Between 2000 and 2005, fifteen (n15) enucleation and thirteen (n13) evisceration operations were performed, giving a total of twenty-eight (n28). Of this number, three had died (n3) and two (n2) were out of the country. Only eight (n8) exenteration operations were performed during that period.

The corneal transplants performed on a monthly basis ranged between six and fourteen (n6-14), including all the procedures performed to nourish the ocular surface prior to the actual procedure like amniotic membrane transplant (AMT) and ex-vivo stem cell allograft transplant (ESCAT).

Besides the clinic, the Unit has a nine-bed eye ward that caters for forty to forty-five (n40-45) patients a month. This unit provides a five-day service for patients with eye problems, diseases or injuries. It is a short stay for all patients with medical problems and those who are going for corneal transplant, enucleation, and evisceration. Patients are kept for observation prior to and after surgery until they are fit for discharge or transfer to other wards.

3.3.2 Research population

According to Parahoo (1997:218), population refers to “the total number of units from which data can be collected”, such as individuals, artifacts, events or organizations. Burns and Grove (2007: 40) describe a population as “all elements that meet the criteria for inclusion in a study”.

In this study, the population consisted of adult men and women who had undergone an operation to remove an eye (enucleation or evisceration) between 2000 and 2005 and were attending their follow-up clinic at the Queen Victoria Hospital (QVH) in the Corneo-Plastic Unit.

3.3.3 Sample and sampling technique

Polit and Hungler (2003:234) define a sample as “a representative portion of the population under study”. Sampling is a process by which the sample is selected such that research findings can be generalized to the population. Bassett (2001:66-67) states that qualitative research does not require a large sample that is selected in a random manner, because qualitative studies seek to describe experiences rather than collect numbers for statistical analysis.

Holloway and Wheeler (2003:128) state that the sample size does not influence the importance or quality of the study. Furthermore, in qualitative research there are no guidelines to determine sample size; but the sample size depends on the purpose of inquiry. In qualitative research persons, situations and events most likely to yield information-rich data about the problems are selectively chosen. This is known as purposeful sampling. In some instances, sampling might continue until data saturation has been achieved (Holloway & Wheeler 1997:142).

In this study twenty-four (n23) patients who had had an eye removed either by enucleation or evisceration in the Corneo-Plastic Unit from 2000 to 2005 were identified as possible participants as they formed the population to be studied. Of these twenty-three patients (n23), seven (n7) were purposely selected to participate in the study. The sampling was therefore non-probable and purposive. The inclusion criteria were that the selected respondents could either be male or female and should

- have undergone the operation between the years 2000 and 2005
- be willing and able to critically examine their experiences and their responses to the situation, and share their experiences or perceptions with the researcher
- be attending the Corneo-Plastic follow-up visit
- be living in United Kingdom and
- be fluent in English
- permit the use of an audio tape recorder

3.3.4 Data collection

Data collection is the precise and systematic gathering of information relevant to a research problem using data collection instruments which can be in the form of questionnaires, interview schedules and guides, field notes and records and/or artifacts (Burns & Grove 2007:77-78). In a qualitative study the most common data collection methods used are interviews, observation, field notes and examination of written texts and artifacts.

3.3.4.1 Data-collection instrument

In this study an interview guide and patients' records were used to collect data. An interview guide is a formal research instrument that is used to collect especially qualitative data.

- **Structure of the interview guide used to collect data in the study**

The interview guide comprised of two sections. Section A provided for the collection of demographic data. Most of this information was retrieved from the participants' files. Where necessary, clarifications and verification of information in the files were done with participants during the interviews. This section provided the researcher with the participants' characteristics such as age, gender, marital status, living conditions and employment status.

Section B comprised of a semi-structured open-ended core question, the aim of which was to explore participants' emotional experiences and feelings following the removal of an eye, through enucleation or evisceration. The core question was: **“Tell me about your feelings, emotions and experiences following the operation you had. You can start from the time you were told that you had an eye condition that might require that the eye be removed.”** Thereafter the question was followed by probing questions on feelings, emotions, experiences, appearance and adjusting to visual loss and support.

The participants were not required to follow any structured pattern, probing merely guided the researcher throughout the interview and was used to clarify areas which were also not clear to the researcher. The interview guide had a broad outline of possible items for investigation that were developed from the existing literature to provide baseline data on which the interview would proceed.

Heap (2004:2) points out that semi-structured interviews have the following advantages:

- They are non-threatening.
- Rich data can be gathered relatively cheaply and easily.
- Interviewers can establish rapport with participants, clarify questions and draw out responses.
- The participants' manner of thinking can be captured.
- They allow flexibility to explore responses through probing.
- They enable researchers to tackle complex topics.
- They assist researchers to define variables in the exploratory stage.

In this study, the main disadvantages of the semi-structured interviews were that:

- They aroused painful emotions, as participants were required to remember experiences that were uncomfortable.
- There was an element of forgetfulness as participants had to recall memories of their experiences in the past.
- **Pre-testing of the interview guide**

Pre-testing of instruments involves the administration of a data-collection instrument to a small sample of participants to determine whether it is clearly worded and easily understood (Polit & Beck 2004:728). Pre-testing of the interview guide was conducted on two patients who had undergone eye surgery but were not involved in the study. The testing of the interview guide was conducted at the researcher's place of work and was tape-recorded to ensure the correct usage of the tape recorder.

Pre-testing of the interview guide provided the researcher with an opportunity to evaluate issues such as the

- length of time to be taken for each interview
- interview techniques to elicit information
- flow of the interview based on the responses and possible comments that could be made by participants (Polit & Hungler 1995:650)
- irrelevant aspects that should be removed from the instrument

3.3.4.2 Data-collection method and process

Data-collection strategies in phenomenological research often focus on in-depth interviewing of individuals so that their experiences and the meaning they give to those experiences are expressed. In this study, the researcher conducted interviews with participants who had undergone removal of an eye through enucleation and evisceration at the Queen Victoria Hospital, Corneo-Plastic Unit to explore their emotional experiences in this regard. An interview is a specific kind of conversation where the process is partially guided by the researcher's intention of covering a specific area of interest, while at the same time the participant is encouraged to talk freely about the subject under investigation. According to Mouton and Marais (1996:43-44), an interview as a method of data collection, provides accurate data and a clear picture of the phenomenon under study. In the interview, the researcher facilitated the

respondents' descriptions of their experiences following removal of the eye. Bracketing and reflexivity were applied before and during data collection, so that the phenomenon under the study could unfold without hindrances or contamination from the researcher's biases, knowledge or experience with ophthalmic patients.

It was important to note that these interviews might provoke anxiety and distress. A psychotherapist was made available on standby in case she was needed to assist patients if they became distressed by the interview. Participants were informed of this arrangement. The interviews were scheduled according to the participants' choice. Those who lived nearby preferred morning hours and their appointments were scheduled for morning sessions. Those who had a long way to travel preferred afternoon sessions. The interviews lasted between thirty to forty-five minutes per session.

The Corneo-Plastic Unit was selected as the meeting place. A quiet room at the end of the clinic was chosen and found appropriate for the purpose.

An interview guide assisted the researcher to focus on important issues, control the interview within the perspective of the study and collect similar data from all the respondents. The interview was initiated by a semi-structured and open-ended question, followed by probing questions depending on the participants' verbal response.

The sequencing of the questions depended on the participants' answers. This method allowed participants to express their experiences in their own words, with no limitations that would be imposed by a structured interview. The techniques used increased the credibility of the findings, prevented researcher bias and facilitated an approach to the phenomenon without preconceptions.

A face-to-face one-on-one interview was conducted with each participant until a point of data saturation was reached, that is, the point where the stories became repetitive and did not add any new information to what had been already obtained (Baptist 2002:1). A tape recorder was used after obtaining permission to do so, to ensure that all information was captured.

3.3.4.3 Data management

The researcher brought structure and order to the mass of data through organisation and

management. During the interviews, data collected were tape-recorded and, where necessary, field notes were taken by the researcher to enrich the data collected. Note-taking is an important activity that allows researchers to collect as much data as possible during an interview and assists in making meaning of observations made. Holloway and Wheeler (2002:237) maintain that although note-taking is an important activity; it may interfere with participants' concentration. In this study, the researcher informed the participants prior to the interview that notes would be taken during the interview. However, the use of a tape-recorder made note-taking less vigorous.

A tape recorder was used to ensure adequate coverage of narrative details for subsequent analysis. All the tapes, notes and transcriptions were cross-checked and labelled. The tapes were kept as long as they were needed for writing the report.

- **Organisation of data**

Holloway and Wheeler (2001:239) describe codes as labels for sections of data. Coding proceeds towards the development of major themes and preliminary categories, which become the tools to sort and clarify subsequent information. In this study meaning units were extracted from the data collected. Similar meaning units were clustered together and from these categories and subcategories emerged.

- **Data analysis**

Data analysis is the organization and interpretation of data collected during fieldwork for the purpose of discovering important underlying dimensions and patterns of relationships (Polit et al 2001:383). De Vos et al (2002:339) describe data analysis as a challenging and creative process characterised by an intimate relationship of the researcher with the participants. Henning et al (2004:127) add that data analysis in qualitative research is an on-going, emerging and interactive non-linear process. Similarly, in this study data analysis continued simultaneously with data collection. Data were read through over and over to identify emerging themes, categories and sub-categories.

Coffey and Atkinson (1996:189) emphasise that qualitative data analysis needs to be conducted with rigour and care. Phenomenological research analysis starts as soon as the first data are collected. These may consist of no more than a single interview. When researchers prepare to attend to the data, the first task is to clarify own preconceptions about the phenomenon under

study. This is known as “bracketing”, suspending the researcher’s meaning and interpretation as much as possible and entering into the world of the individual interviewed (Tesch 1990:92). In this study bracketing and reflexivity were applied during data analysis to hold in abeyance preconceived beliefs, opinions and experiences of the researcher about the phenomenon under study (Polit & Beck 2004:253). Streubert and Carpenter (1999:12) stress that bracketing does not mean making judgements about what was observed or heard, it means remaining open to data as it unfolds.

Researchers need to consider whether they can address any bias in data collection or analysis by interviewing a participant a second time or reanalysing the script in question. In addition, Holloway and Wheeler (2001:263) maintain that researchers should reflect on their own actions, feelings and conflicts experienced during research to achieve credibility. To do this, the researcher validated data collected by going back to participants to confirm whether the interpretation of the data collected was correct or not.

Verbatim transcription of the interviews allowed the researcher to gain full and rich data. Holloway and Wheeler (1996) state that researchers should transcribe their own tapes to enable immersion in the data. Morse and Field (1996:107-108) maintain that the first major task in analysing interview data is for the researcher to become extremely familiar with the data.

After the completion of tape-recorded interviews, the researcher replayed the tape, listening carefully to the content as well as the questions asked. The tape-recorded responses during the face-to-face interviews were manually transcribed verbatim and read over and over to gain a sense of the whole. The researcher used Tesch’s (1990:93) steps of data analysis as follows:

- The researcher listened to the text units to get the feeling and emphasis. Verbal and non-verbal proceedings were written down. After going through all the transcripts, the researcher rearranged similar topics in groups by forming columns, labeling major topics, unique topics and leftovers.
- Field notes were reviewed as additional data.
- The researcher read and reread the transcripts to acquire a sense of the whole. The background knowledge was noted by recalling observations and experiences.
- The researcher noted the core facts and ideas to identify the topic and wrote them down in the margin. The researcher then observed the organised data to check if new categories or sub categories emerged.

- The most descriptive wording for the topics was found and converted into themes, categories and sub-categories. The aim was to reduce the total list of themes by grouping topics that related to each other together. Significant statements that pertain to the emotional experience under investigation were extracted by
 - making a list of topics as identified in the data per interview
 - organizing these into clusters
 - sorting according to research objectives
- Themes were then used to provide full descriptions of the experience.
- Where necessary, the researcher returned to the participants' original descriptions of experiences for accuracy and validity.
- Data material was put together in one place according to each theme, category and sub-categories; and preliminary analysis was performed to extrapolate meaning out of the emotional experiences as expressed by the participants.
- Recording was done to reflect on analysed data.

The actual data analysis occurred when the researcher read the entire data set. The researcher immersed herself in the data by reading and rereading the verbatim transcripts and dwelt on the data, in order to gain a sense of the whole.

- **Measures to ensure trustworthiness of data collected**

A research project is trustworthy when it reflects the reality and ideas of the participants. Trustworthiness in research depends on the extent to which it delves into the participants' experience apart from their theoretical knowledge (Streubert & Carpenter 1999:61). In this study, trustworthiness was ensured by putting aside preconceived ideas about the phenomenon under investigation and by returning to the participants to determine whether the description was a true reflection of their experience.

Lincoln and Guba (1985:301) and Krefting (1991:217-221), state that trustworthiness involves credibility, dependability, confirmability, and transferability.

- (i) **Credibility**

Credibility establishes how confident the researcher is with the truth of the findings based on the research design, participants and context. Credibility exists when the research findings reflect the

perceptions of the people under study. Krefting (1991:217) maintains that credibility requires adequate submersion in the research setting to enable recurrent patterns to be identified and verified. In this study credibility was enhanced by:

- **Prolonged engagement**

This refers to the investment of sufficient time to learn about the study units, test for misfortune, and build trust and generally repeat the procedure central to the study design. According to Polit et al (2001:313), prolonged engagement is important for building trust and rapport with the participants. Krefting (1991:217) adds that prolonged engagement allows the researcher to check perspectives and allows the participants to become accustomed to the researcher. Siegle (1999:1) adds that prolonged engagement counters distortion from both the researcher and the researched, and limits the researcher's biases and compensates for effects of unusual or seasonal events.

In this study, the researcher was a registered ophthalmic nurse and the participants were patients she had an association with for a substantial period of time even before their operations. Much time was invested in data collection and analysis. The interviews were tape-recorded to capture the original responses and the responses transcribed verbatim to maintain the original meaning. The interviews were conducted in English as participants were fluent in English.

- **Member checks**

During the interview, member checking consisted of the researcher restating, summarising, or paraphrasing the information received from a participant to ensure that what was heard or written down, was, in fact, correct. Following data collection, member checking consisted of reporting back preliminary findings to the participants, asking for critical comments on findings, and potentially incorporating these critiques into the findings. Both forms of member checking assisted to add accuracy and richness to the final report.

The researcher continually tested her data with participants during the interviews by asking for clarification. Siegel (1999:2) maintains that member checks assess participants' intentionality, correct errors, provide additional volunteer information and put participants on record. It also creates an opportunity to summarise, analyse and assess the overall adequacy of data in addition to individual data points. Participants were given a summary and interpretation of the interviews to validate the researcher's accuracy and understanding of meaning attached by participants to

their experiences (Holloway & Wheeler 2001:258; Krefling 1991:219).

- **Persistent observation**

According to Siegle (1999:1), researchers need to consistently pursue interpretation in different ways in conjunction with a process of constant and tentative analysis. The researcher looked for multiple influences and searched for what counted and what did not count. This was achieved by diligent recording of face-to-face interactions with participants and tape-recording sessions.

- **Triangulation**

Krefling (1991:219) describes triangulation as a powerful strategy for enhancing the quality of the research, particularly credibility. Agostinho (2004:9) and Krefling (1991:219) state that triangulation is an approach that utilizes multiple data sources, in order to confirm or validate research findings. The primary goal of triangulation was to gather a more complete understanding of phenomena.

The best way to elicit the various and divergent constructions of reality that exist within the context of a study is to collect information about events and relationships from different points of view, by asking different questions, seeking different sources and using different methods (Siegle 1999:1; Krefling 1991:219).

In this study triangulation was achieved through the use of different data-collection methods. Data was collected by means of tape-recorded in-depth one-on-one interviews with participants to obtain in-depth information on their emotional experiences following the removal of an eye. Full notes from observations were also made during data collection. Triangulation enabled the researcher to distinguish true information from one with errors.

- **Peer debriefing**

Peer debriefing refers to exposing a researcher's analysis and conclusion to colleagues or other peers on a continuous basis for the development of both design and analysis of the study. Siegle (1999:1) adds that debriefing is done by colleagues who are outside of the context of the study but have a general understanding of the study. They can review perceptions, insights and analysis in order to provide a "devil's advocate" approach and help in developing the whole

research process. The researcher liaised with medical consultants in the unit, experienced colleagues and study supervisors on an on-going basis regarding the research process, data collection and analysis.

(ii) Dependability

According to Polit et al (2001:315), dependability refers to “the stability of data over time and over conditions”. Crawford, Leybourne and Arnott (2000:11) add that dependability is parallel to reliability as conducted in quantitative studies. Siegle (1999:3) contends that in dependability an inquiry must also provide its audience with the evidence that if it were replicated with the same or similar participants in the same context, the findings would be repeated.

However, Lincoln and Guba (1985) cited in Libbarkin and Kurdziel (2002:199) hold that in qualitative research reliability can almost never be achieved, as participants change over time and identical data can never be collected twice. Therefore, the researcher ensured dependability by collecting and recording information correctly. The raw and analysed data were scrutinised by the study supervisors for accuracy and stability. An audit trail was established to enable others to judge the study for dependability.

(iii) Transferability

According to Holloway and Wheeler (2002:255), transferability means that the findings of a research project can be applicable to similar situations or participants. Libbarkin and Kurdziel (2002:197) add that transferability refers to the degree to which the findings can be transferred to other settings, contexts or populations. The ultimate goal of all research is the establishment of the value of research outside of the immediate context under study.

The ability to apply conclusions to other settings depends strongly upon a researcher’s ability to document the original study, giving subsequent researchers an opportunity to identify all the variables inherent to that context. The knowledge acquired in the context will be applicable in another; and those that carry out research in another context will be able to apply certain concepts that were originally developed. Crawford et al (2000:11) describe transferability as parallel to generalisability that is applicable in quantitative studies. It is relative and depends entirely on the degree to which salient conditions overlap or match. In this study it was verified through thick description of data.

- **Thick description**

Rich or thick description refers to the way in which data is converted into coherent and detailed descriptions of the phenomenon under study. Because transferability in a naturalistic study depends on similarities between sending and receiving contexts, sufficient detailed descriptions of data were collected in context and reported with precision to allow judgment of transferability (Siegle 1999:1-2). Mathie and Camozzi (2005) are of the opinion that thick description is actually the basis for qualitative analysis. From the description, it was possible to build analytical explanations about what was going on in the phenomenon under study. The rich and thick descriptions enhanced greater possibility of a thorough interpretation and analysis of the data.

- **Purposive sampling**

Another way to assess transferability is purposive sampling, which is used to maximize the range of specific information that can be obtained from and about the context by knowingly or purposely selecting locations and participants who are knowledgeable of the phenomenon and will be able to provide meaningful information thereof (Siegle 1999: 3). The researcher asked the Oculo-Plastic consultant and the Unit manager to help select the appropriate key participants who would provide rich data about emotional experiences.

(iv) Confirmability

Siegle (1999: 3) refers to confirmability as the extent that the research findings can be confirmed or corroborated (confirmed) by others. Polit et al (2001:315) add that confirmability refers to neutrality or objectivity of data; that is, the extent to which the researcher is aware of or accounts for individual subjectivity or bias.

In this study confirmability focused on how bracketing and reflexivity were applied to ensure that the research findings were the result of the study and not of the researcher's assumptions and preconceptions. The raw data was made available on tape and transcripts securely stored to make sure that the information could be confirmed. Other strategies for enhancing confirmability included searching for negative cases that ran contrary to most findings and conducting data audit to pinpoint areas of bias or distortion.

According to Holloway and Wheeler (2002:255), an inquiry audit can be used to trace the data to

their sources. In this way the researcher's path of arriving at the themes, categories and interpretation can be followed. The supervision of the academic and clinical supervisors added credibility to the research process followed.

Lincoln and Guba's (1985) six categories of records in an audit were also used to ensure credibility:

- Raw data were kept on audiotape recordings.
- Data reduction and analysis was done, such as condensed notes from verbatim interview transcriptions.
- Data reconstruction and synthesis products such as themes, categories, interpretations and inferences were developed.
- Process notes (procedures and design strategies, trustworthiness) and notes (verbatim transcripts) were kept.
- Material related to intentions and dispositions such as the research proposal of the study was kept.
- Instrument development information such as the interview guide and pre-test findings were kept.

3.3.5 Ethical considerations

Ethical considerations relate to moral standards that the researcher should consider at every stage of the research process. Ethical considerations are important aspects especially in qualitative research because the in-depth semi-structured nature of discussions that are pursued often raise issues that are not always anticipated. To adhere to the ethical requirements, the following were done.

- **Gaining entry into the setting**

Institutional approval was sought by presenting the proposal to the Research and Ethics Committee West Sussex, Research and Development Committee Queen Victoria NHS Foundation Trust, and the University of South Africa, Department of Health Studies Research & Ethics Committee. The research proposal was reviewed by peers in Brighton University to ensure that the study fell within the standards of the Trust. Permission was sought from the Queen Victoria Hospital NHS Foundation Trust Director of Nursing and the Corneo-Plastic Unit

Director of Ophthalmology Group to be able to access the patients' files and receive guidance from the Unit team.

- **Securing informed consent and voluntary participation**

Informed consent in qualitative research is an ongoing process of informed participation. Holloway and Wheeler (1995:224) posit that informed consent is problematic in qualitative research, as participants cannot be fully informed at the beginning of the study because the research context is in constant flux. The researcher could not tell the participants exactly what data would be dealt with even if she wanted to do so. This was due to the fact that qualitative research focuses on the participants' meanings and interpretations. Further the researcher developed ideas that were grounded in data, rather than testing previously constructed hypothesis. However, the participants needed to be told about the overall purpose of the research and its main features as well as the risks and benefits of their participation.

According to Henning, Van Rensburg and Smit (2004: 73), participants need to know that their privacy and sensitivity will be protected and what is going to happen with the information they provide. Ritchie and Lewis (2003:67) add that informed consent should be based on an understanding that participation is voluntary. Consent can be given in a written format or verbally. If the researcher does not know in advance the questions the participants might be asked, or what potential risks might be involved in the future, this must be communicated to the participants at the outset.

In order to ensure that the participants were well informed about their role in this study, the researcher gave a full disclosure of the study. The process and purpose of the study, the type of interview and other data-collection procedures were explained. This enhanced the self-determination of each potential participant

The researcher ensured that participants were not coerced to participate in the study. Participants voluntarily participated in the study after giving informed consent in writing. They were also informed that they were free to withdraw from participation from the study if and when they so wished regardless of the consent signed (see appendix C).

- **Anonymity and confidentiality**

Qualitative research can be intrusive, therefore, the researcher needed to be sensitive and apply her communication skills. The researcher worked with a small sample and it was not always easy to protect their identities. “Thick description” entailed describing everything in great detail and in so doing the identities of the respondents could be uncovered (Holloway & Wheeler 1995:227). Ensuring anonymity and confidentiality regarding information provided enhanced the participants’ right to privacy. Confidentiality was an important issue when dealing with anonymity. Permission to use the tape recorder was sought before the interview could start and all the participants consented to its use. Anonymity and confidentiality was also ensured in that the recording was edited and any names mentioned deleted from the tape. The following measures were also taken:

- The respondents’ names were not recorded on the interview guide response sheets.
- Code numbers or pseudonyms were used. For example, P/1, P/2 codes were used to identify participants interviewed.
- The identities of the participants were not revealed in the report and would also not be revealed in publications of the study.
- The data were not shared with any other person apart from those actively involved in the analysis of the data.
- Tapes and transcriptions would be erased one year after the research had been finished, when all the publications had been effected.

3.3.6 Limitations of the study

The following problems were anticipated as contributing to errors in data collection.

- **Situational contaminants**

Some situational factors could influence participants’ responses adversely including their being aware of the interviewer’s presence. Environmental factors such as lighting, temperature and noise might impact on their reaction. Some of the above contaminants were excluded by arranging a well lit and ventilated room towards the end of the clinic where the noise was perceived to be less. A “Don’t disturb” sign was put outside the interview room to limit interruptions during data collection. The tape recorder was placed at the strategic point between

the participant and the interviewer to capture the voices well. The telephone line was diverted to another office

- **Response set bias**

Rigour is more difficult to maintain, assess and demonstrate in qualitative research. Therefore, research quality is heavily dependent on the individual skills of the researcher. Personal characteristics might influence responses to questions resulting in the phenomenon of subjectivity. The interviewing technique, explanation of purpose of the research to participants and assurance of confidentiality as well as the signed consent form were used as measures to reduce the possibility of the above aspects.

- **Transience**

Temporary state of anxiety and fatigue might influence the participants' responses. The potential distress to the participants was minimised by the researcher being clear about her role and boundaries and by ensuring that the duration of the interview is not unnecessarily extended.

- **The use of assistive devices in data collection**

The use of a tape recorder could pose a problem with device failure and the participant being uneasy with its use. In this study the researcher requested the permission of the participant to use the device. She practised how to use the recorder prior to the interview by testing her capabilities on two other colleagues to familiarise herself with its operation. The researcher brought along spare batteries in case of power failure.

- **Researcher's bias**

The aspect of the researcher being the main conductor of the interview in her workplace might have led to distortion of the findings of the study. The researcher practised bracketing as well as reflexivity to overcome the problem. The researcher also went back to the respondents to verify and clarify their responses. The tapes and transcripts were made available to the supervisors to control analysis and interpretation.

- **Time**

The volume of data made analysis and interpretation time consuming. Data were analysed as they were collected.

- **Generalisability**

As data was collected from a few respondents, the findings could not be generalised to a larger population.

3.4 CONCLUSION

This chapter discussed the research design and methodology, including the research approaches, research setting, population, sample and sampling technique, data collection, data-collection instrument, pre-testing of the data collection instrument, trustworthiness and ethical considerations. A non-experimental, qualitative, exploratory-descriptive approach that is contextual in nature was used.

Chapter 4 discusses the data analysis and findings.

CHAPTER 4

Data analysis and findings

4.1 INTRODUCTION

A thematic analysis was made following the verbatim transcription of the phenomenological interviews. The main themes, categories and sub-categories were identified then utilized as a framework for a phenomenological description account including quotations from the participants. The guidelines by Tech's open coding method of data analysis (Creswell1994:155) were followed. Information provided by the participants was classified according to themes, categories, sub-categories and meaning units denoting the emotional experiences of patients who had enucleation or evisceration. The most expressive descriptive words for the expressed emotional experiences following removal of the eye were identified as categories and sub-categories and the findings were validated with literature.

4.2 PRESENTATION OF BIOGRAPHICAL DATA

The biographical data yielded the following characteristics as presented in table 4.1.

Table 4.1 Presentation of biographical data

Parameter	Value	Frequency	Percentage
Age n-7	31-40	3	42.6%
	41-50	3	42.6%
	51-60	0	0%
	61 and above	1	14.8%
Gender n-7	Male	3	42.2%
	Female	4	57.8%
Marital Status n-7	Single	2	28.4%
	Married	3	43.2%
	Co-habiting	1	14.2%
	Widowed	1	14.2%
Living conditions n-7	Husband no children	2	28.5%
	Husband & children	1	14.3%
	Girlfriend	1	14.3%
	Daughter & grand children	1	14.3%
	Boyfriend & nephew	1	14.3%
	Parents	1	14.3%
Employment Status n-8	Employed	2	25%
	Unemployed with benefits	3	37.5%
	Unemployed without benefits	2	25%
	Retired	1	12.5%

Parameter	Value	Frequency	Percentage
Date of surgery n-7	2000	1	14.4%
	2003	3	42.4%
	2004	2	28.8%
	2005	1	14.4%
Type of Surgery n-7	Enucleation	3	42.2%
	Evisceration	4	57.8%
Cause of surgery n-7	Trauma	2	28.5%
	Congenital	3	43%
	Infection	2	28.5%

4.2.1 Findings on the biographical data

The participants' ages ranged between 31 and 61. These comprised of three males and four females. Two participants were single, three married, one co-habiting and one widowed. All seven participants lived with others. Two with their husbands and had no children, one lived with a husband and two children, one with a daughter and grandchildren, one with a boyfriend and her nephew, one with his girlfriend and the last with parents. Two participants were employed and five were unemployed. Of the five, three had benefits while two were without any benefits. One was retired. Only one participant had his surgery in the year 2000, three in 2003, two in 2004 and one in 2005. Out of the seven participants, three had enucleation and four evisceration performed.

The reasons for enucleation or evisceration are outlined hereunder.

4.2.2 History of eye problems resulting in enucleation and evisceration

Corneo-Plastic Unit is a referral and teaching unit, which treats patients with long standing eye problems. Two participants had trauma to their eyes, the first had penetrating injury to the eye; an arrow went into his eye. Attempts were made to restore his vision but failed, he had corneal grafts that rejected and the patient also presented with intra-ocular pressure and with time lost sight completely in that eye, hence removal of the eye. The second participant had had problems with the eyes and vision was also restored by cataract removal and corneal grafts. She unfortunately sustained injury and ruptured the eye ball. Nothing much could be done to save her eye at the time.

Three of the participants had congenital eye problems. The first had congenital glaucoma and microphthalmos in one eye. There was no vision in that eye. The pressure was uncontrollable and unbearable, such that the participant welcomed the decision to remove the eye. The second

participant had congenital glaucoma and buphthalmos. The cornea appeared extremely cloudy and scarred and the patient could not bear the pain. The third participant had Riley Day Syndrome (an inherited disorder that affects the function of nerves throughout the body) and the patient presented with long standing corneal opacities and glaucoma. There was no vision in that eye and the eye had infection (endophthalmitis). The participant had requested that the eye be removed.

Two participants had Stevens Johnson Syndrome as an underlying cause. Stevens Johnson Syndrome is also called multiform major; which is the disorder of the skin that can affect the eyes, characterized by painful, blistering lesions on the mucous membranes of the mouth, throat, genital area and eyelids. The most cited cause is an adverse allergic drug reaction. One of the participants had the condition since the age of six years when she reacted to septrum syrup that was given for a sore throat. She had several operations on one eye and the better eye was the one she lost following cataract extraction whereby she contracted endophthalmitis and her eye was removed instantly. The other participant had Stevens Johnson Syndrome six years prior to her surgery. She had reacted to nurofen tablets. She was referred to the Corneo-Plastic Unit for further management, had amniotic membrane to nourish her ocular surface, but she later presented with endophthalmitis. She requested removal of the eye because of severe pain.

From the history obtained from records and interviews, the seven participants had different eye problems that finally led to the removal of the eye. The above history is summarized in the following table (table 4.2).

Table 4.2 History of eye problems before the eye was removed

Participant no:	History
Participant no: 1	Penetrating injury with an arrow to the eye; had corneal grafts that rejected, developed intra-ocular pressure and finally lost the eye. Pain was the major problem
Participant no: 2	Had had corneal grafts and cataract extraction previously, then had a blow on the eye that resulted in eyeball rupture
Participant no: 3	Had congenital glaucoma and microphthalmos with uncontrollable intra-ocular pressure
Participant no: 4	Congenital glaucoma and buphthalmos and severe pain
Participant no: 5	Riley Day Syndrome and endophthalmitis with a lot of pain
Participant no:6	Stevens Johnson Syndrome as a result of drug allergy, had endophthalmitis post surgery with pain
Participant no: 7	Stevens Johnson Syndrome as a result of a reaction to medication, had severe pain

4.3 OVERVIEW OF THEMES AND CATEGORIES DERIVED FROM INTERVIEW DATA

Narrative data was analyzed manually and arranged into meaning units; the purpose of which was to organize and provide structure to elicit meaning from information collected (Polit et al 2001:381). The researcher created categories and sub-categories from the data obtained from the seven participants' interviews. Major themes emerged from this exercise. This was achieved by developing a conceptual file for each theme following the steps provided by Tesch (1990) as cited in Creswell (1994:155).

In this study, the three major themes that were identified were: feelings and emotional experiences following removal of an eye; facial appearance and adjustment to visual loss.

4.3.1 Theme 1: Feelings and emotional experiences of patients following removal of an eye

Emotional experiences following removal of an eye could be traced from the period a diagnosis that would finally result in enucleation or evisceration was made. In this study negative emotions like distress, shock, denial, depression, anxiety, fear, being upset, guilt/reproach, anger, embarrassment and positive emotions like relief and joy, provided the bases for the reactions of the participants, first, to the diagnosis and proposed management based on the prognosis, and then to the outcome of the management thereof. Emotions are complex and arise from many sources (Schoefer and Ennew (2005: 4). Community Services for the Blind and Partially Sighted (CSBPS) (1996:1) assert that although each person's reaction to the diagnosis of serious irreversible vision loss is different, for many this is devastating. According to De Leo et al (1999:339), one typical reaction of a patient to sight loss is depression of varying duration and

severity. Further, these authors maintain that the reaction to sight loss may persist over time. Feelings, emotions and responses of participants on being told that the eye will be removed are reported in table 4.3.

4.3.1.1 Negative emotions

- **Shock and denial**

Cruse (1999:3) asserts that the initial reaction to loss of sight is often one of shock or denial and these reactions may be experienced in different ways. In addition, Crossland and Culham (2000: 21) state that the initial manifestation of this stage is usually a transient state of denial which is a basic psychological defense mechanism. Jones and Diner (1992:1) contend that realizing that one will be facing the future with partial vision can come as a shock; the people will always experience a sense of shock whether sudden or gradual. Basically almost all participants expressed shock even though some requested the eye to be removed. Table 4.3 illustrates the participants' responses of shock and denial.

- **Anger**

According to CSBPS (1996:1-2), anger comes from a sense of frustration that there is nothing that can be done by the patient, doctors and the family to prevent vision loss. Crossland and Culham (2000:21) assert that this anger can lead to significant problems with relationship. "***I was angry at my doctor...at myself.***" In this case the patient realizes the full impact of loss and may express emotions through tears, sadness, envy, rage and resentment, and questions such as ***why me? Who is at fault?*** are common (Hospice Net 1996:1). Table 4.3 represents the participants' anger.

- **Guilt and self-reproach**

According to CSBPS (1996:2), the patient feels guilty about the things not done to save the ailing eye, usually blames self, health professionals and significant others for something that was neglected around the time of loss, for example: "***I am angry at myself...at my doctor for not...***" These feelings attempt to understand why the loss has occurred. In most cases guilt is normal, though not justifiable. In table 4.3, the participants expressed their feelings of guilt and self-reproach.

- **Fear/anxiety/distress**

CSBPS (1996:2) asserts that feelings of fear about the loss can affect the patients' ability to make decisions or think about day-to-day activities. Patients can become pre-occupied with their loss. This feeling of inadequacy may lead to panic, as tasks once mastered are now frustrating and difficult to accomplish. *“I was frightened that the infection will... I had a nagging fear...”* These emotions are expressed in table 4.3 below.

4.3.1.2 Positive emotions

- **Relief/acceptance**

According to Hupfeld (1999:2) positive emotions reflect important co-occurrences among positive mood states. Further, it is associated with constructive activity and adventure. For example: *“I was pleased that they finally removed it.”* Madu (2004:113) posits that acceptance involves acknowledging the disability or loss and ignoring its limitations.

Allen (1989:640) asserts that the feelings and responses to visual loss are related to subjective interpretation of the experience and although one's response to visual loss is unique, there are meanings which are shared. In this study there were different as well as similar emotions and feelings that were expressed by participants. These were also in varying degrees. They emerged in categories that were descriptive of the experiences of the participants. There were negative as well as positive feelings and emotions, all of which were expressed in many ways. See table 4.3

Table 4.3 Feelings, emotions and responses on being told that my eye will be removed

Category	Sub-category	Meaning Units
Negative feelings and emotions	Shock/Denial/	I was very, very shocked... (P2) I remember feeling shocked and frightened and scared...(P2) I remember clutching my head just to let a silence scream...I'm going...No...oh!...and just begging. I was so shocked...I remember sh...shaking (P2) Although it was a shock ... shock did not hit me until after the event (P 5)
	Confusion/doubt	I had mixed feelings ...I felt bad that part of me would be missing... but I also knew that I would no longer have pain ... but the news still shocked and scared me (P4)

Category	Sub-category	Meaning Units
	Disbelief/scared	<p>I was cross...I was confused ...I didn't want to do it...but I wanted it done...(P6)</p> <p>I remember saying please don't let it (Infection) go to the other eye...(P2)</p> <p>I was just shocked really...I just couldn't believe it...(P4)</p>
	Fear/anxiety/distress	<p>I thought I needed to sleep over this information ... that my eye needs to be removed... when I got home I was worried still ... I couldn't believe this has come to what it seemed to be ... you know...(P4)</p> <p>I was really, really frightened...I couldn't believe it; it didn't soak in...(P2)</p> <p>Fear! Feeling like...I can't describe the feeling exactly... but I suddenly had hot flushes.....I was scared but sort of relieved....(P6)</p> <p>I was frightened that the infection will go to the other eye...(P2)</p> <p>I had a nagging fear that I could actually go blind in the seeing eye...(P3)</p>
	Nervous	<p>Although, I requested it... I was a bit nervous about and sad at the same time...Obviously losing an eye is a big thing...(P1)</p> <p>I was laughing and giggling all the way to the operating theatre ... I am a very strong person ... (5)</p>
	Apprehensive/scared	<p>I think I was probably be a bit apprehensive, and a bit scared...Eh...Yes; I was....I was absolutely scared...(P3,5)</p> <p>When I saw it in writing I got really scared and the first time, I said no! I am not doing it...I cancelled everything ... I had a lot in my mind. (P6)</p>
	Anger/Guilt/Self-reproach/upset/ blaming	<p>I was angry at myself...angry at my doctor....(P2)</p> <p>I was very upset at the time... 'silence'... They could have done something with it before they took it out ... but I also realized that it had gone too far. (P4)</p>
	Disappointment	<p>Obviously it was a bit upsetting to have to lose an eye.....(P1)</p> <p>I thought the pain will stop but it hasn't ...I am a bit disappointed...(P1)</p> <p>I completely understood ... I would have liked to have been ... it.. made clearer to me what in fact caused the infection and why this is happening to me ... (P2)</p>
Positive/ acceptance	Relief	<p>I wasn't bothered about it at the time because I was in a lot of pain....(P4)</p> <p>I thought it was valid ... I was having a lot of pain ... there was no point in keeping it ...(P3)</p> <p>I was actually desperate to be pain free due to perforation and infection ... the doctors were still hopeful to save it but I wanted it out (P7)</p>

Category	Sub-category	Meaning Units
		<p>I requested it... Yes...many years of pain, socially isolated, and just coping with life...I had had enough...(P7)</p> <p>Positive...I just said..."do it" (P7)</p> <p>It was me who requested it ... I felt good ...(P1)</p> <p>I kind of ...expected it...I thought well here we are; we finally arrived...(P1)</p> <p>I asked them to get rid of it...I wanted to cut my losses and just have the operation...(P5)</p> <p>Well I wanted it done...I just expected that it was a big step and irreversible... I was happy to have it done. (P5)</p> <p>I was totally sure that it was the right decision (P5)</p>

Five participants were positive about the surgery; they actually requested that the surgery be performed. They expected it and indicated that it was a sort of relief to them. The five participants also accepted the notion that it was a big step that was irreversible. One participant out of these although positive and reportedly strong willed; still mentioned that it was shocking to have this big operation. This reaction is in line with that provided by Living with Vision Loss [On line]. The organization contends that even those who have a very positive attitude towards their surgery tend to feel depressed when frustrated by new demands in their daily routine. These researchers found that 50% of people with sight loss were experiencing some type of depressive effects even four years later. Cronin (1993) cited in Hehir (2000: 10) reports on a survey undertaken on patients at the Royal Marsden Hospital where 25% of patients were depressed as a result of altered body image.

The rest of the participants expressed their feelings as shock and denial, disbelief, fear, anger and apprehension. One participant was so shocked at the news that she initially cancelled the operation only to get it done at a later date. Hospice Net (1996: 1) confirms these feelings by stating that immediately people learn about pending significant loss, feelings of disbelief set in and most often several of these emotions occur at the same time, perhaps in different degrees as was the case in this study (see table 4.3).

4.3.1.3 Pain in the affected eye

Another major factor that had to be taken into consideration was pain in the affected eye. In almost all the instances, the operation was performed to relieve pain, promote comfort and improve the quality of the life of individuals.

Pain is subjective and therefore personal. Its existence depends on what is communicated by the affected individual (Aydede 2005:4). Migliori (1999:81) confirms that conditions that result in blindness almost always result in severe eye pain. Also, patients in chronic pain may suffer from depression; and become addicted to narcotics. Although, the seven participants had different underlying causes leading to the removal of the eye they all had one thing in common “Pain.” Pain was mentioned by all participants as the factor that had a great influence on the decision taken on whether to keep or lose the affected eye as indicated in table 4.4.

Table 4.4 Feelings and emotional reactions to the removal of an eye based on pain experienced

Category	Sub-category	Meaning Units
Discomfort	Pain	<p>I was in a lot of pain... (P 1, 2,3,4,5,6,7)</p> <p>I could not sleep at night....(P7)</p> <p>I was in so much pain and I was actually rude to the nursing staff (P7)</p> <p>I had pain for such a long time; the pain stopped me from working (P1)</p> <p>I could not sleep at night because of severe pain...I felt enough is enough (3; 6)</p> <p>I wanted the eye removed because of pain...it was unbearable (2; 4;5)</p>

4.3.1.4 Feelings and emotions about information communicated

Other responses relate to the reaction to the manner in which information was communicated as reported by participants.

Although four participants were positive about the reason given for the proposed surgery and had actually requested that the surgery be performed, they were particularly dissatisfied in the manner in which information relating to the nature of the operation was given. To them this was too technical, inadequate and/or insensitive. For instance, one participant felt that she did not understand the finer details given; as the information was too technical. One felt she was controlled and felt compelled to go with what she was being told. One felt that the information he gathered did not match the outcome.

I didn't realize that there would be side effects afterwards...I mean...the pain I now get; I also thought the eye would look better than I think it did....Hmm! it looks horrible...(P1)

I wasn't actually shown pictures, or people who had artificial eyes... I didn't realize that there will be a problem with eye movement.(P1)

Really only in words by my consultant....(P3)

One other participant felt the reason given could have been made clearer. One felt that efforts could have been made to save her eye. One had mixed emotions, she felt bad that part of her was taken away; although on the other hand she understood that she would be pain-free as she was told.

I don't think he explained to me to understand...my knowledge of understanding was not clear. He did not simplify the information; some things were technical

No...not really...I thought there could have been more information particularly about what I have just told you about.....pain....(P1)

I completely understood...I would have liked to have been...it.. made clearer to me what in fact caused the infection and why this is happening to me...(P2)

No...I think at the time that's all he should have given me because I was in such a shock....but I think I should have been given much information between that point and when the eye was actually removed because I had to wait a day...My consultant...I didn't see him again.....I desperately wanted to speak to him more, because I trusted him....(P2)

Insensitivity is evidenced by the following:

Basically he just sort of said...eh! I think it was the only way to say. He just said straight out; "We're going to have to remove the eye because the infection is so bad" In a way it was of the best because it was brutal...(P2)

My consultant... I think it was given to me the only way it could have been given really...(P2)

To be honest...I think a lot of it wouldn't have soaked in because I was frightened...All I could remember was that I was told; "We've got to do this." So I really felt like I had no choice; it was like I was being controlled; I just had to go with what people were telling me to do...(P2)

For those who found the information satisfactory, The following:

I think it was adequate for my nerves because after all it was said and done. So basically I had enough information; definitely it was a right move....(P3)

I think it was valuable to the point of much reassurance as I could really have expected to receive.....(P3)

I was positive and found the information valuable because I was worried about the condition of my eye then; I felt relieved in a way...(P5)

Very valuable; as I said ...being in isolation due to infection could have isolated me from everybody, but it didn't ...the nurses and doctors were all good....(P5)

For me it was good to know the expected outcome ... honesty... about not being sure about how would the eye be removed....(P7)

Excellent! My doctor explained what they had to do in great detail...(P7)

4.3.1.5 Questions asked by participants from which emotions could be elicited

To substantiate the information provided here above, participants cited questions that they asked in relation to pain, disfigurement, operation process in terms of the nature of the operation and recovery period, quality of life thereafter, infection and general anxieties associated with loss. These questions further expressed the feelings and emotions of patients who are to have/have their eye removed. According to Sen (2005:1), many patients' anxieties may be allayed by explaining what they should expect following the operation. This should include things like swelling and bruising, pain which is expected in the first 24-36 hours following the operation. The patient must be reassured that pain killers would be given to ease the pain and the necessary support will be available.

Pain: According to Hehir (2000:10), fear of pain and disfigurement often feature high on the agenda of the patients' needs. One participant was concerned about the pain, as the reason for removal of his eye was to alleviate pain.

Well! I did ask if there will be pain afterwards.....(P1)

Disfigurement: Most of the participants wanted to know about their looks following surgery. Tolley and Henninger (1991:18) affirm that most of the patients who had removal of an eye wanted realistic information about cosmetic results and wanted opportunities for plastic procedures to improve fit and appearance of the prosthesis explained to them. Kolberg Ocular Prosthetics (2005:1) add that the important factor after surgery for the patient is the appearance, ocular prosthesis, its colour and size and the person's feelings about the prosthesis. Further, Migliori (1999:99) contends that disfigurement of the face distorts a patient's social interactions and sense of wholeness. Patients must therefore be prepared to cope with the cosmetic changes that follow removal of the eye and the usual sense of isolation they can develop from perceived disfigurement of the face. Questions asked included the following:

I wanted to know how they would take it out....(P2)

Just what is involved....how much they would take away?.. (P2)

Will the operation affect my tear duct?...Will I be able to cry...Will it affect my looks?...will the artificial eye function like a normal eye?.....(P6)

Will people notice that I haven't got an eye? Will I look different? (P2)

Time frame: Most of the participants wanted to know how long the operation would take. How long would the recovery time be and the length of time before they could get the artificial eye to replace their lost eye. Morris (1991:26) posits that the health professionals need to establish what the patient already knows, and how the patient feels about the operation. Also, find out what the patient wishes to know, as other patients may want to know full details while others will be content with basic explanations.

Questions asked included the following:

How long will the procedure last? How will I feel afterwards? (P5)

How soon will the false eye be fitted in?...I just couldn't imagine having no eye...(P2, P3)

Will evisceration cost me less than enucleation? (P5)

Well I wanted to know about the recovery time....the length of time before I get the prosthesis...artificial eye...(P7)

Quality of life: Vader (1992:705) posits that the incredible role that vision plays is never recognized until it is compromised. One participant wanted to know whether her tear duct would be affected and would she be able to cry through the socket, will the artificial eye function like a normal eye? Will she be able to blink and move her eye?

Will the operation affect my tear duct?...Will I be able to cry...Will it affect my looks?...will the artificial eye function like a normal eye?.....(P6)

Will people notice that I haven't got an eye? Will I look different? (P2)

Will the infection go to the other eye? ... How can you be sure?... I wanted to know where this infection came from...promise me it won't go to the other eye...There seemed to be no one to reassure me...(P2)

Will my other eye be affected? I am scared. (P3)

Visual hallucinations: According to Gross, Wilson and Dailey (1997:221), hallucinations are frequently reported in patients after ocular trauma, surgery or progressive visual degeneration. In particular hallucinations are often experienced by patients following enucleation.

Kraut and Lopez-Fernandez [2002: 207] contend that the images are usually familiar forms and are described as variables in colour and clarity. They might persist for months, and they usually disappear spontaneously. One participant reported having hallucinations:

I was getting hallucinations...I don't know what hallucinations are...but I was told I am hallucinating ... I thought it might be septicaemia ...I wanted someone to explain to me...because I thought I was going mad...I was just seeing things...I wanted to know why I am seeing things...why I am imagining things and panicking...I wanted to know why I am seeing things... why am I kind of acting a bit mad. (P2)

Infection: The first few weeks the socket is constantly checked for signs of infection, and the patient is normally put on antibiotics for ten days. One participant wanted to know about the infection she had. The participant was very nervous about the shocking news, because she lost the good eye. She needed to be reassured that the other eye will not be affected.

Will the infection go to the other eye?... How can you be sure?... I wanted to know where this infection came from...promise me it won't go to the other eye...There seemed to be no one to reassure me...(P2).

Fear/panic/anxiety: Kraut and Lopez-Fernandez (2002: 208) point out that any threat to vision can cause anxiety, and the loss of one eye in active individuals can cause great agitation that can further cause psychological trauma if not treated adequately.

I was getting hallucinations...I don't know what hallucinations are...but I was told I am hallucinating...I thought it might be septicaemia...I wanted someone to explain to me...because I thought I was going mad...I was just seeing things...I wanted to know why I am seeing things...why I am imagining things and panicking...I wanted to know why I am seeing things... why am I kind of acting a bit mad. (P2)

Further, these writers state that the condition of the remaining eye may determine an individual's recovery process. For instance if the remaining eye has poor visual acuity the recovery process will take more time and effort. The suddenness of new monocular condition as opposed to gradual loss has a great impact in the patient's life. Most of the participants were nervous that their remaining good eye may be affected.

Will my other eye be affected? I am scared. (P3)

One patient was also frightened that she would not be put to sleep during the operation because she had problems with anaesthesia and hated the fact that she would hear everything being done and said during the surgery.

Well I was nervous that I was not going to be put to sleep, so I was just crying...I was nervous about my other eye. (P4)

4.3.1.6 Feelings and emotions after removal of the eye

The feelings and emotions after the removal of the eye mainly deal with the psychological impact of loss and body image. In this study, these were similar to the initial emotional reactions like pain, depression, shock/denial, guilt/reproach, anger, fear, upset, disappointment and for some relief and joy. Similarly these were expressed differently. McBride (2005: 36) contends that some patients may appear distracted, distressed, angry, disbelieving while others may appear stoical and brave, thus concealing the impact of what is happening within them. This latter reaction actually delays the process of taking constructive action.

One participant expressed anger because he had lost his job because of the pain long before surgery. He felt his life had been put on hold. He had ambitions, but had lost that with the diagnosis of the eye problem. Two participants felt depressed by the fact that they lost their good

eyes. Both of these participants were on antidepressant. One was stressed by the fact that she had no support from her family. Three participants had started to rebuild their lives and were hopeful of a better quality of life, two had guide dogs and three had embarked on their studies because they felt it was time to be strong and move on with life. One participant expressed concern about the changes in his socket and the condition of his eye lids (see table 4.5).

Table: 4.5 Feelings and emotions expressed post-operatively

Category	Sub-categories	Meaning Units
Negative emotions	Anger/ Blaming	I am still fed up...I still have pain and I am unable to work because of it...Life has been put on hold...I can't work again. When you got ambitions and you can't do what you wished for; is bad...(P1)
	Disappointment	I thought the pain would stop ... but it hasn't... I am a bit disappointed (P1) No ... I have not found the operation valuable ...(P4)
	Depression/ Stress/Hope begins to return	I feel very depressed at times...I believe I would be better if I would come off anti-depressant...I mean I am ok when I take them...when I stop I fall back into depression...(P2) I feel stressed about it all the time, and the fact that I lost the good eye gets me down...I am thinking about it all the time...(P4) (Almost Tearful) I have been through a lot because I had to deal with everything by myself. I had no connection with my sister and was at the point of being suicidal...(P6)
	Appearance/ Embarrassment	The bottom part of my lids has become sunken...and I believe it can disrupt your false eye...it can actually fall out...and it did fall out....that was embarrassing...I feel good that some corrective work has been done...(P3) Taking it in and out ...cleaning it ; I sometimes put it back in the wrong way...“upside-down” because I cannot see well in the other eye.....(P4)
Positive emotions	Relief	Wonderful! I wish I had done it earlier because there was hardly no vision in that eye anyway...(P5) I feel fine now; it sometimes gets dry a lot, but no pain. Well I was made aware of that because of my Steven Johnson Syndrome; that I would experience dryness...I use lubricants for that...(P7) I had counseling sessions that helped me a lot. I feel good that I can tell somebody how I feel...getting things out of my chest is sort of healing for me...(P6)
	Self confidence and rebuilding self	I have started my studies with the University of Roe Hampton this month, which is a challenge for me and I am happy at the moment...(P2)

Category	Sub-categories	Meaning Units
		<p>I feel happy now I have enrolled with the college and I would like to study about Child Care...(P6)</p> <p>I now have a guide dog which is very helpful, and I feel like I am getting my life back...I can go to places with my dog...(P2, P4)</p>

4.3.1.7 Pain and disfigurement post-operatively

Progress on the experiences of pain and disfigurement post-operatively

Several authors outline the process of healing and pain relief as extending over years. The following outlines emotions on pain and disfigurement post operatively.

- **24 HOURS**

Moderate pain is expected post-operatively and occurs during the first twenty-four hours. This pain resolves 2-3 days post operatively. Patients should be made aware of this and that analgesics are given to ease the pain (Wills Eye 2004-2005:2).

Three of these participants were relieved that they had no pain when they woke up. One was relieved that the remaining eye was not affected by surgery; that he could see and was not focusing much on pain. Another was relieved that the infected eye had been totally removed. Although the latter was relieved, he was regretful that he allowed this to happen. Three of the participants experienced much pain when they woke up.

- **ONE WEEK**

In the first week a small amount of bruising and some numbness of the surrounding tissue are normal. Also, a small amount of a pinkish discharge may be expected for the first three to four days and this will gradually diminish with time (Hehir, 1999: 11). Four participants noticed swelling, bruising and a bit of discomfort. Pain was better compared to the pain they experienced before and shortly after surgery. Apart from pain, disfigurement and pending disability usually start to manifest during this period. According to McBride (2005:36), loss of an eye is many people's greatest fear; it conjures up images of dependence and helplessness, even loneliness and abandonment. Therefore, when people are faced with the loss of an eye and sight they express

their feelings, fears and anxieties. In this study two participants were in shock especially when they saw the socket for the first time.

The most traumatic experience my wife had was when they removed the bandage...she almost fainted when she saw my socket because she was not prepared for that...(P3)

It's a big shock isn't it? I have been expecting it. I was prepared for it but it was a big shock...You lose something that you had all your life and it's gone...and that was it really....(P1)

One participant was very emotional. She reported to have felt exhausted and was crying all the time and could not believe that she lost her eye.

One participant was experiencing flash backs and could not sleep at night.

The above signs and symptoms should start to improve after the first week

- **4-6 WEEKS**

In the following four to six weeks, although one participant was still experiencing pain and was still bruised, the swelling was improving. Most of the participants were getting over their pain, swelling and bruising. There was still some discharge noticed. American Society of Ocularists (2002: 1) maintain that under normal circumstances patients who have had an enucleation or evisceration should be referred to the ocularists for fitting of the ocular prosthesis 6-8 weeks post-operatively. However, the Ocularists assert that patients' healing is influenced by the technique and implant material used, age, previous treatments and other medical conditions.

One participant reported that she was not improving emotionally and was crying a lot, not sleeping, not eating and did not want to go out nor speak to anyone;

the realization that I will never see light again hit me hard....

- **3 MONTHS**

Within three months one participant was looking forward to having an artificial eye and he was not thinking about a missing eye at all. CSBPS (1996:2) asserts that when hope begins to return, positive results usually manifest. One participant's eye lids started to shrink and she had an implant operation which she thought was too painful, but she felt good about it because it was done for a reason. One participant expressed concerns about the counseling sessions she received; she felt she was not ready to move on, she needed more counselling sessions.

Three more participants felt comfortable with everything. One expressed excitement because he had his first mould for his prosthesis and was hoping to return to normal and significant activities.

- **6 MONTHS**

Two participants reported problems with irritating; sticky mucous discharge from the socket. They felt it was a bit of a nuisance and embarrassing and that affected their social life. One was starting to feel better emotionally though at times she felt down and believed that if something traumatic could happen to her she would not be able to cope. One participant felt the journey to the hospital really affected her a lot: "*It took them several attempts to make me a proper artificial eye*". One participant was going through a depression phase, because of a rift between her and one of her family members whom she relied on. Some of the factors that contribute to depressive behaviour as indicated by Madu (2004:115), are lack of support from family members and friends, the level of one's self-esteem, level of stress and personal motivation. This participant was beginning to doubt her decision.

- **ONE YEAR**

By the end of the year, one participant reported that he felt that not much was done for his pain problem which at the moment had cost him his job. He felt that the doctors did not seem to understand his problems. One participant felt very angry with the consultant and the hospital because she felt she had never been given the information she needed. She wanted to understand why and where the infection came from, and why her. She felt losing her eye impacted badly on her other remaining eye because she does not have enough vision in the remaining eye.

Three participants reported having started to rebuilding their lives as one had enrolled with the University of Roe Hampton for a Bsc in Integrative Counselling, one with the college for Child Care and another with the University of London for a PhD in English literature.

The table below depicts some of the reactions explained above.

Table: 4.6 Progress report on the pain and disfigurement post-operatively

Category	Sub-categories	Meaning Units
Negative emotions	<u>24hours</u> Pain	<p>I imagined that the pain would just go because I was in absolute agony before it was removed....but I woke up in agony that lasted for another day...I was in a lot; lot of pain...I was not expecting that...I was quite disappointed at that...No discharge, but oh... the swelling ... it looked like a black eye...(P2)</p> <p>It was still very painful...I just couldn't believe it...it was shocking...(P4)</p> <p>When I woke up I had pain that lasted for a coupler days.....(P6)</p> <p>It was still very inflamed, uncomfortable and painful...(P1)</p>
	Traumatic/Shock	<p>The most traumatic experience my wife had was when they removed the bandage...she almost fainted when she saw my socket because she was not prepared for that...(P3)</p> <p>It's a big shock isn't it? I have been expecting it. I was prepared for it ... but it was a big shock...You lose something that you had all your life and it's gone...and that was really...a ...sh...(P1)</p> <p>I wasn't fit to come in...but I remember I was an emotional wreck...I was sitting there at the waiting room crying my eyes out. I just bawled...I don't think the consultant was prepared for the emotional side of things; he didn't realize that I have been affected. (P2)</p>
	Regret	<p>I felt glad in a way because there was no going back....at the same time I felt regretful that I allowed them to take out my eye....It was mine no matter what...(P6)</p>
Positive emotions	Relief	<p>Ooh! Hmm! Relief, relief that eh...I woke up and I could see from the seeing eye, because there was this little nagging doubt at the back of my mind that there was a possibility that I might lose sight in that eye...so it was a relief...a state of relief...(P3)</p> <p>Relieved really...(P5)</p> <p>Relieved that I was in no more pain...(P7)</p>
Negative emotions	<u>One Week</u> Devastated	<p>I was in such a devastating state...I remember lying in bed feeling so...o...exhausted...I didn't want to move. I was just thinking...I can't even get up to see the doctor; I am so tired; I just wanted to cry all the time. (P2)</p>
	Pain	<p>I had a lot of pain in my head.....I had flash backs in my headthey kept on coming towards me.....(P4)</p>

Category	Sub-categories	Meaning Units
	Discomfort	A bit of discomfort but compared to the pain I had prior to surgery it was minimal....(P5)
	Shock	I was shocked at seeing the redness in my socket....I asked myself...Oh! Lord! What have I done?...(P6)
Positive emotions	No pain	There was swelling and bruising but no bleeding, the socket was not painful at all.....(P3)
Negative emotions	<u>4-6Weeks</u> Pain	It took a long time to settle down.....I was still in pain....(P1)
	Depression	I started to cry a lot all the time at nothing...I wasn't sleeping.....I wasn't eating, I wasn't drinking too much, I didn't want to go out, I didn't want to speak to anyone...I just couldn't believe of what had happened to me...I wasn't myself....(P2)
	Depression and devastation	When I started to realize that the left eye had been affected by me using it and I could not rely on it.... the dawning realization that I was not going to see better out of it " Hit me! " really it hit me....(P2) The things were settling down a bit but I was going through the process of not having the eye...and it was very painful to bear...(P4)
Positive emotions	Marked improvement	The socket was getting comfortable, the bruising and swelling went down ... (P3) Everything was fine ... there is a little bit of discharge still ... now and again ... but I know I was well on end ... (P5) I was having a bit of discharge and bruising ... things were settling well anyway ... (P6)
Negative emotions	<u>3 Months</u> Pain	I had implant operation and it was a painful and uncomfortable operation, but because it was for a reason I was fine with it...My eye lids were shrinking as well...(P2)
	dissatisfied	I had only six sessions with my counselor...I really think they should have given me more counseling sessions...(P2)
	Depression	This is the period that my sister and I had a physical row ...it was so bad that I went into depression, I did not want to talk to anybody...I became suicidal...I was wondering if I did the correct thing, I just could not cope...(P6)
Positive emotions	Improvement	It started to settle down.....a little bit better....(P1) Wonderful! Because by that time I had had the first moulds...(P3) Things were settling down though I still experienced flash back (P4) After three months I was not thinking about it at all, I was looking forward to having a prosthesis...(P5) I've never given it a second thought...I remember it of course...things like that are never forgotten...but it is gone ...it is history...(P7)

Category	Sub-categories	Meaning Units
Negative emotions	6 Months pain	I still got a lot of pain although it is not as bad as before ...but I can't do anything ...like work...(P1)
	Anger/anxiety	I am angry with my doctor to be honest... because I wrote to the hospital to ask about my infection; and they told me what it was but never told me anything about where it came from. When something like that happened as part of healing...you needed to know why; where it came from...and why me...(P2)
	Frustration	The sticky mucous is the only frustrating thing that stops me from totally enjoying the outcome of my surgery. (P3)
Positive emotions	Relief	I am glad that it is done because at least it looks like an eye and I have no pain...(P4)
Negative emotions	One Year Poor prognosis	The biggest impact of me losing my right eye was the fact that it impacted badly on my left eye and I ended up having... I think... eighteen operations in that period on the run so... it was the biggest strain because I was constantly getting the anaesthetics, constantly having to stop my life and go to the hospital. (P2)
	Relief	I am glad that it is done because at least it looks like an eye and I have no pain...(P4) I am now beginning to build my life; I have enrolled with college and would like to study about child care. I am receiving counseling as well...(P6)

4.3.1.8 Family's reactions following the loss of the eye

Migliori (1999:100) maintains that family members face the same obstacles as the patient and some are unable to address feelings of fear, guilt or helplessness engendered by the surgery. Two participants had prepared their families because their operations were planned. Devastation was realized in four families whereupon two participants' families were devastated by the news; one by the fact that the participant made the decision to go ahead with the surgery unilaterally. The anger of this family has, according to the participant persisted. The participant felt that the family was apportioning blame on her for making this decision.

They were so...o angry! That's all I could describe...they were all so angry. My mother the first day she was in shock...second day....she started saying...How could this happen? (P2)

The other family was devastated because they did not expect the news.

I think it hit my parents quite hard.....I think my mother especially probably due to the fact that when I was younger, she used to make all the decisions about when they were going to re-graft. Whereas now that

decision was out of her hands and in my hands...but I think it hit them harder than me to be honest...(P5)

All this is supported by Blaycock et al (2005:2) who maintain that the family members may have their own emotions and feelings concerning the loss of an eye. This, somehow interferes with the ability to provide adequate support for the patient.

Like the patients, some families may hide their feelings. This was the case with one participant who was, therefore, never sure how the family felt about his surgery. One participant felt her family members were angry and they needed some answers as to why and what happened that she lost her eye. One participant felt that his mother was disappointed that the decision was not in her hands but in his hands. Two participants felt that their families, even though sorry that they lost an eye, were relieved that they had no pain anymore and the operation had been done.

One participant found it difficult to tell how his family felt because they did not tell him. One participant felt her family members were still very angry to date, because they felt that they had never had answers about how her eye got infected. One participant felt her family did not care, especially her sister who was too close to her. Three participants felt that their families were comfortable and were used to things as they were.

Table: 4.7 Family’s reaction following removal of the eye (then and now)

Category	Sub-categories	Meaning Units
Negative reactions	<u>At hearing the news:</u>	
	Devastation and helplessness	My mother was devastated....it was like... she made me feel like it was the end of the world. My husband was very calm; and so said logically; “that’s what they have to do; and we’ll get through this”.(P2) My sisters thought of me losing my eye ...to them it was like losing your head, they were... from the cosmetic point of view ... they really were devastated for me....(P2)
	Upset/angry	How could this happen? Why has this happened to you? ... My sisters were angry, they were looking in the internet ...trying to get some helpful information for me...(P2) They feel angry about the hospital...like we’ve never got an answer as to where the infection came from...and they are constantly on my back: Have you gone to the solicitor?...have you done this?...(P2)
	Pretence	We are not in a speaking terms with my sister, I believe she does not care anymore...my dad is now closer to me...(P6) They tend to hide their feelings...(P1)

Category	Sub-categories	Meaning Units
Positive reactions	Relief	They have been expecting it for a long time.....because I got them ready for it...I did tell them....(P1) They knew already but it was a bit upsetting for them...(P4) My wife was relieved that I would not have pain anymore; yet she felt sorry that I was going to lose part of my body....she is a strong woman....I am happy to have her as my only encouragement...(P3) All my family were pleased that I had no pain; they were relieved that I was ok...(P7)
	Support	My dad was confused he didn't understand anything about the eye problems, so he didn't seem to show any emotions really.....My sister was very supportive until we fell out.....(P6) My wife is now comfortable with everything...she helps me with drops....we are all in this together...(P3) I think they are now used to me ...they do not say anything anymore...(P4) I don't think they really think about it anymore...I mean they realized that it was my choice of having it done....(P5) Everything is normal...(P7)

4.3.2 Theme 2: Facial appearance

Kolberg Ocular Prosthetic (2005:1) maintains that one thing that is not often considered at the planning phase of enucleation or evisceration, which becomes an important factor after surgery, is the person's appearance post-operatively. Patients are always concerned about their facial features following removal of an eye.

4.3.2.1 Feelings about the appearance of the socket

In the researcher's judgment most of the participants did not dwell much on how they looked like. What featured most were their feelings at the time. One participant found it quite shocking and shameful, yet he rationalized about the whole thing that; "*For me removing a bad, deformed eye that did not see was like taking out a useless piece of gut...*" He only felt he let himself down by allowing the first the condition to happen and second the operation to be done. The other participant who did not have good vision in the remaining eye and who surprisingly had been positive about the outcome of his surgery; said: "*when I felt a soft empty space;*" *It felt strange but I was not shocked by it at all; I felt relieved.*" One participant was concerned about

the way she looked. She even changed her glasses. One participant was just curious to see the socket.

Table: 4.8 Feelings about the appearance of the socket

Category	Sub-categories	Meaning Units
Negative feelings	Mixed feelings: Shock/ Rationalization	Shocked...it's almost a bit of shame actually...is that strange to say?... I feel like I sort of let myself down in a way really....by allowing it to happen in this way.....But I am glad it got done; don't get me wrong ... but a bit of me is gone. When I think of my eye not moving, I thought to myself that there is no difference in having your appendix removed, because it is a useless piece of gut ... of the intestines....and if the eye is deformed or in any way bad...why keep it there? That's how I rationalized the whole thing.....(P3, P4) No not at all...No I didn't expect that...it was just a shock...(P4) I don't really think I had a firm expectation of what it would feel like.(P5) No I didn't expect to see an empty space, red mass...(P6) I suppose it was...and it wasn't. I didn't know what to expect...nobody told me what to expect. (P3)
	Remorse	I was very scaredthe shock of seeing the red mass in my eye was too much. I didn't expect to see such a big hole. I could not look into the mirror and do my hair. I was scared to look at the eye. I even changed my glasses to darker ones so that people should not see what I have done. (P6) I didn't see it because I can't see much in the remaining eye anyway...but when I touched my eye I felt the hard thing...It really hit me that I didn't have an eye...you know. Realizing that I would never see light through that eye; has still not totally sunken. (P2)
	Worry	No ...I was worried about my remaining eye. (P2)
Positive feelings	Relief/ acceptance	That's a tricky one....you just get the feeling that it's final and it's done and there is no going back. (P1) Yes....(P1) I never saw my eye socket....I mean I felt around it and you know....it was soft and empty....it was very strange but it didn't shock me or disturb me. I felt a bit of relief that the big thing that was killing me had gone. (P5) I was Intrigued, curious that's all. (P7) Yes it was all what I imagined and expected....(P7)

According to Migliori (1999: 99) removal of the eye elicits a range of complex emotional responses. Some of these emotions are positive while others are negative. To this effect two participants had imagined and expected the outcome of their surgery; but five did not have a firm

expectation of how the socket would look like, and seeing a hole there shocked them. One did not actually know what to expect.

4.3.2.2 *Feelings about the artificial eye*

All participants reported having been fitted with a conformer whilst waiting for the artificial eye. They all did not like the conformer. Two participants had received their artificial eye in four months time after surgery; four in six to eight months and one in ten months time. Five participants were comfortable and pleased with their artificial eye. One of them actually expressed self confidence as the prosthesis improved her appearance. At first one was not pleased as she thought she did not look herself but now she feels comfortable with it. One was dissatisfied because she had to come for many visits as the hospital staff could not get it right sooner.

Table 4.9 Feelings about the artificial eye

Category	Sub-categories	Meaning Units
Negative Emotions	Sad	It was uncomfortable, they had to adjust the lids and I had to come to the hospital now and again. I was crying all the time I still couldn't believe what had happened. (P4)
	Doubt	At first as I was looking into the mirror I didn't like itIt was not me. Also wearing it was painful...I feel better now; I am comfortable with it now...(P6)
Positive Emotions	Comfort	It was a lot more comfortable than that plastic thing (Conformer)(P1)
	Joy/ Happiness	I was pleased ...glad ...I didn't have to wear that glass thing (Conformer)...(P2)
		Wonder...absolutely wonder...I looked in the mirror and I thought; "that is really beautiful"....(P3)
		Oh! Great; it was great....(P5)
	It was a good feeling ...it has improved my appearance....(P7)	

4.3.2.3 *Change in facial and eyelids appearance*

Two of the participants had not noticed any changes in their appearance. One noticed that the eyelashes were lying on the prosthesis because the eyelids are shrinking. One noticed that the eye socket was sunken. One noticed that the eyelids were drooping. The other noticed that the eyelids did not close properly and the affected part of the face appeared flatter than the rest of the face.

Shrinking of the eyelids, sunken socket and drooping of the eyelids are some of the late complications of removal of the eye. Secondary surgery is performed to rectify the defects (Moshfeghi et al 2000: 290-293).

Table 4.10 Change in facial and eyelids appearance

Category	Sub-categories	Meaning Units
Negative responses	Poor appearance	<p>I can't see what it looks like but I believe that the eyelashes are lying on it...and there is a sticky and gooey substance on it...I don't know what you call this body fluid...and my eye lids are shrinking as well...(P2)</p> <p>Yes...my socket is sunken; and the doctor had to sew up the eyelids...(P4)</p> <p>Yes; there is a change....my eyelids are now droopy and I am in the process of having them being lift up...(P6)</p> <p>The only thing that I recognized when I looked in the mirror was that my eyelids were not closing properly. The right side of my face looked flatter than the left side from the side view.(P7)</p>
Positive responses	Good appearance	I don't think so; my mom used to clean it and said it looked nice and pink...(P5)

4.3.2.4 Family's reaction towards the socket

Two of the participants did not show their families their eye socket. One reported discomfort with showing family members her eye socket. One said her family members were not keen to see it, they did not like it. Five of these participants did show their family members their eye sockets. One participant felt that his family wanted him to keep the prosthesis on all the time. One participant thought her family pretended that they were not affected by it or that they hadn't noticed it. One of the participants said his wife was really shocked and nearly fainted. One said her family was squeamish while the other two reported their families' reaction as curious (see table 4.11)

Table: 4.11 Family's reaction towards the socket

Category	Subcategories	Meaning Units
Negative reactions	Apprehension	They have not seen it...They don't like it...(P1)
	Embarrassment/Shame	No! Nobody...not even my husband...I don't want anyone to see it.
		I think it's like showing someone your stump when you have lost your leg. I think it's private...(P2)
		Only my wife because she had to help me care for my socket....(P3)
	uncomfortable	Not immediately but three days later; shortly after I have left the hospital...(P5)
		They don't want to see the socket or the inside. They want me to keep the prosthesis in all the time...(P1)
Yes! my sister and my father only because they asked otherwise I wouldn't have shown them....(P6)		
Avoidance/pretence	My sister was squeamish and kept on asking if it wasn't painful ... My father kept on asking: Did you have to do it?.....(P6)	
Shock/ Avoidance/ embarrassment	They all pretended that they were not affected by it... but my dad cried.	
	My mother was shocked she kept on saying...Isn't that dreadful...My sisters pretended they haven't noticed...my little nephews and nieces noticed and asked to look under my dark glasses, and I wouldn't let them.....(P2)	
	My wife was shocked because of the experience she had at the hospital...absolutely shocked.....(P3)	
Positive reactions	Curious	They were so scared at first but I think they got used to it....(P4)
		Yes! I did offer to show them my eye socket...I was positive about it...(P7)
		Well...they were all curious but squeamish...but they finally got used to it.....(P7)
	Satisfied	I showed my daughter...(P4)
Nothing too shocking; I mean they sort of went on with the job....and they weren't disgusted or shocked by it really. They were happy that it was looking healthier....(P5)		

4.3.3 Theme 3: Adjusting to visual loss and the support received

Mogk and Mogk (2004:3) argue that to lose vision as an adult is to experience one of the worst things in life. The shock of vision loss and the adjustment it requires is not just a single individual's adaptation to physical impairment but often affects one's relationships. It prompts changes in roles, duties, profession, living arrangements, travel and communication with spouses, children and society. Kraut and Lopez-Fernandez (2002:207) add that the phases of adaptation include physical and social trauma, shock and denial, mourning and reaffirmation, coping and mobilization and self- acceptance and self-esteem. Although many models of loss assume that after experiencing intense distress, an individual will recover and return to normal function, there are studies that show that many individuals often have a difficult time resolving their problems and continuing with their life. According to Morris (1991:27), patients react differently to the loss of an eye and this is in accordance with the different stages reached in the grieving process.

Participants reported on several aspects that impacted on their adjusting to visual loss.

4.3.3.1 Aspects found difficult to adjust to in relation to

- **Self**

Clarke et al (2003:37) in their study discovered that participants reported a variety of difficulties associated with their conditions. This included dealing with negative reactions from the general public, meeting new people, feeling low self-confidence, and restrictions to social life due to anxieties about being seen in public. This supports the notion that one participant felt that he was very self-conscious about the absence of his eye and felt as if people were watching him all the time. Further, Clarke and Wyn-Williams (2000:14) contend that social encounters become a huge challenge as people stare, point or make comments.

Well the little kids sometimes when I am walking in the streets... shout and say: "Hey! You are blind; what is under your glasses?" or something like that; ... and there is no way, absolutely none... I wouldn't show people my eyes...; it's too private....(P2)

Sometimes people would stare at me especially at night because I have my dark glasses on....well now that I have my guide dog people now understand why I wear my dark glasses at night....so my self consciousness is leaving me.(P2)

One felt that she was not safe to go around her home. She hoped to get a smaller house but that seemed to be taking a long time. She also felt that she was unable to do housework and that had taken her self confidence, independence and sense of security away. Also being unable to sleep got her down. One participant who had lost her balance once did not feel safe going out because she felt very clumsy.

Another participant felt that she could not cope with the fact that she lost her eye. She still felt emotional, guilty and anxious about it. Looking in the mirror was like she was not herself.

- **Family/friends**

McBride (2005: 36) contends that sight loss is often likened to bereavement and, as with major loss in life, people need to grieve before they can move on. This process is however, often helped by timely support from family, friends and professionals. On the contrary, Tolley and Henninger (1991: 18) discovered from their study that the participants appreciated the support offered by the health professionals. The above notion supports the fact that few of the participants in this study did not feel secure around their families. One indicated that she felt weird around her husband; she would rather he did not look at her.

One felt the family or friends seemed to hold back their feelings just to be nice to him. Yet another, felt as though people were watching her when she inserted her artificial eye as she sometimes got it wrong. For yet another participant there was a feeling of the family having drifted away as the family did not provide any support.

- **Relationship with society**

According to Clarke and Wyn-Williams (2000: 14), people, especially children, tend to stare, point or make comments when they come across people with visual impairment; *“Hi! You are blind; let us see under those glasses ...”* One participant felt very small as the children shouted at her in the streets because she wore dark glasses; but now that she had her guide dog she felt safe, and would not have to explain herself to anyone. One participant felt that the only time he

felt apprehensive was when the people were looking at him, while his eyelids were still bruised. At that time he did not have an artificial eye.

Well at work the only time I was a bit apprehensive was when my eye was still bruised and I didn't have an artificial eye but only the plastic shell (Conformer) ... Yes...I suppose I was a bit apprehensive when they were looking at me closely... apart from that they are very supportive ... (P3)

Clarke and Wyn-Williams (2000: 15) also noted that for people who have disfiguring conditions affecting the eye, social interactions are complicated by the role that the eyes play in communication. For instance, the experience of trying to talk to someone wearing dark glasses is not good as the person is embarrassed at his/her appearance and looks down rather than directly at the other person. One participant found socializing very difficult because she could not maintain her normal balance.

I had a problem with balance and I did not feel safe to go out so I preferred to stay at home....(P6)

They don't really know unless I tell them I've got a downside now....otherwise I don't really socialize. (P4)

Kraut and Lopez-Fernandez (2002:211) affirm the above statement that; it is a common complaint from the patients to bump into people or objects.

4.3.3.2 Aspects that helped to adjust to the loss of an eye in relation to

- **Self**

One of the participants did not have anything in particular that helped him to adjust to his loss; however he said he just carried on like nothing ever happened, a condition known as 'Blanking'.

I haven't really done anything special...I just carried on...you got to.....(P1)

According to Crossland and Culham (2000:21), the end stage of the grieving process is the acceptance of the situation. This may take the form of the patient admitting the visual problem to friends, family and neighbours, but more crucially to her/himself. In this study two participants had guide dogs and they were able to go places and that changed their life style.

I keep myself occupied all the time... I do some of the things I used to do....I have got my guide dog from RNIB and I go to places I want to go to ... (P4)

Crossland and Culham (2000:22) further indicate that reorganisation of life to incorporate the visual impairment is the sign that the individual has progressed from depression. In relation to that, three participants, one had enrolled with the University of Roe Hampton and started a degree in Integrative Counseling; one with the nursing college for Child care and the other was pursuing his PHD in English literature.

I am at the university studying but before that I was lecturing languages...my condition has never stopped me from doing all what I wanted to do. Being able to talk to people made me stronger...(P5)

I have never stopped working to date ... probably is because my remaining eye is good (P3)

One of these three participants had opened her network and was meeting with friends of her age for drinks and social gatherings.

Two participants were referred for counseling sessions which they thought was helpful but not enough, as a result one continued with her sessions privately.

The best thing that helped me was the six sessions of counseling that I got with my counselor...that was fantastic. She made me feel solemnly happy....(P2)

- **Family/friends**

Petrowski, (1986:138) argues that the patient whose family/friends make supportive remarks during the adjustment period following surgery copes better with the situation. Normally a patient needs someone close to communicate feelings about the way the prosthesis feels, how it looks, what it costs and if it will affect relationship with the family, friends and colleagues. In this study most of the participants were satisfied with the support they received from their families.

My wife has been very positive from the start....nothing has changed (P3)

Nothing really...my parents are very supportive. (P5)

On the other hand some participants maintained that their family members had never made a great deal out of their loss; and that gave them strength.

They don't even mention it; it is not an issue to them...(P7)

Only one thought her family ignored her and pretended they were not bothered.

They all pretended that they were not affected by it... but my dad cried.

- **Health professionals**

Oehler (1982: 28) contends that the ophthalmic nurse can have a vital role to play about the adjustment of patients to visual loss. Therefore in helping the patients to cope with the loss of vision the challenge for the ophthalmic nurse is to provide preventive rehabilitation to avoid a major interruption of the individual's life style. Most of the participants felt that the nurses had been supportive and treated them with courtesy.

One participant felt two nurses had been outstanding in rendering emotional support, but felt that the rest of the nurses needed more training. Most of the studies confirm the fact that the nurses' failure to give the patient advice and support is due to lack of knowledge about what the person is going through. They suggest that the nurses could benefit from in-service training to develop a better understanding on how to provide emotional support to patients who have lost sight.

Furthermore, nurses can be instrumental both in referring patients to other sources of help and professional psychological support (Donnelly 1987; Hehir 2000; Clarke and Wyn-Williams 2000). According to Tolley and Henninger (1991:18), although empathic, nurses are still under prepared to meet the emotional needs of patients who have had enucleation or evisceration

Five participants were positive about the support provided by the doctors. Of the two who were not positive about the support received from doctors, one felt that the information she received from her doctor was not enough. She still needed some answers about why she ended up losing her eye and how she got the infection. The second participant was not happy with the doctor because he felt the doctor did not understand that he was still having pain that actually cost him his job.

- **Voluntary organizations**

Two of the participants did not want to be involved with voluntary organizations. Three knew nothing about these organization. One had been to a few of them and is now running her own network which was fun because she met with people of her age. One had been to Crisis Team which was offering counseling and had also introduced her to a team called Life Style Changes.

4.3.3.3 Feelings and emotions about self following removal of an eye

Participants were quite communicative about how the operation impacted on their self, that is, self conscious, self confidence, self image and self esteem:

Self conscious: *I'm very self conscious about it.... You meet people for the first time; you can tell they are looking to see what the difference is.... And that makes me feel very self conscious(P1)*

Self confidence: *It is just doing things that need close contact....that concerns me and impacts on my self confidence. Not being able to go around my home. Another thing is; I can't sleep at night since I had my eye removed and this really gets me down. (P4)*

Self image: *My eye looks better now that I've got this artificial eye ...And it's brilliant...I am concerned about my left eye which is all stitched up;*

taped and all sort of things...it looks awful and I think it is the one that has taken my self image away ... (P2)

I haven't a good movement when looking to the left or right ...apart from that nobody notices at all. So my self- image is not affected in either way. (P3)

Self esteem: *Although I have never had sight in that eye, I couldn't cope with the fact that my eye was removed. I felt very emotional about it; I was anxious and felt guilty that they took part of me. I did not want it to be taken away I wanted to keep it. When I first looked in the mirror I was really shocked because I didn't see in me; a person I've known for so long.(P6)*

Self pity/uneasy: *I had a problem with balance and I did not feel safe to go out so I preferred to stay at home....(P6)*

Acceptance: *Well I didn't have to because I was blind in that eye from birth. What I didn't have I don't miss. (P3)*

Absolutely nothing...It was an emergency; it wasn't usefully sighted anyway and I saw tiny out of it; I was virtually blind in that eye. So it was easier to let it go. (P5)

No problems...in fact I had no sight in that eye and I was in constant pain; so it needed to be removed to improve my quality of life.....(P7)

For me it was all over; I have the eye that is quite good to feel normal. So looking at my artificial eye is as good as it can be and nobody notices unless I tell them. (P3)

4.3.3.4 Aspects that did not help to adjust to the loss of vision

There were definite aspects that were stated by participants that did not help in the adjustment to the loss. These are outlined in table 4.12 below.

Table 4.12 Aspects that did not help participants to adjust to the loss of an eye

Category	Sub-categoriess	Meanings Units
Negative aspects	Lack of support	I had nobody to lean on...everybody drifted away and I was left alone. You know; people are not interested in problems.....(P6) Fine! often forgotten about it.....(P7) Well at work the only time I was a bit apprehensive was when my eye was still bruised and I didn't have an artificial eye but only the plastic shell (Conformer) Yes...I suppose I was a bit apprehensive when they were looking at me in close detail, apart from that they are very supportive.....(P3)
	People staring	I used to get stress from people staring because I was wearing dark glasses.(P6) They make no difference to me...(P5)
	Self conscious	More conscious of the eye not moving well and appearing cross eyed.....I feel tired of looking straight on to people.....(P7)

4.3.3.5 Difficulties encountered in relation to adjusting to the loss of vision

One participant felt that the period taken to make his prosthesis really stressed him out because he had to wear dark glasses to be able to move around. According to Clarke and Wyn-Williams (2000:15), interaction may be complicated by the role eyes play in communication. Anything that disrupts that can make people feel uncomfortable.

One participant felt that being brought early to the hospital did not help her at all; and that she could have been left alone. The same participant felt that the period for her counseling sessions was not enough. A year would have been appropriate. Two of the participants were not happy to be sent home with a conformer without proper preparation. Two felt there was lack of preparedness in relation to what to expect post surgery as far as the pain was concerned. Also one felt her family could have been better prepared on what to expect before showing them her socket. One felt that her accommodation problems could have been dealt with for her own safety and security.

I don't see well I live in a three bed room house upstairs, I need a smaller house where I can be able to go around by myself, but the Local Council has not yet provided me with a safe house. The doctors did not refer me to the Local Council so that I can get a better accommodation....(P4)

Mogk and Mogk (2004:2) assert that new vision loss, especially on the one eye presents difficulty with depth perception. There tends to be miscalculation in relation to position leading to embarrassing falls.

I had a problem with balance and I did not feel safe to go out so I preferred to stay at home....(P6)

One participant reported that she lacked family support hence she was suicidal. De Leo et al (1999:341) maintain that family members may also present with denial, refusal to accept and overprotection reaction in an effort to camouflage their own feelings towards their relative's sight loss and the difficulties the loss entails. One was bothered by the people who were constantly reminding her of what she used to be and look like. She couldn't cope with that.

People were talking about the problem I had; constantly reminding me of what I used to look like instead of what I've got now.....(P6)

Table 4.13 Difficulties encountered in relation to adjusting to the loss of the eye

Category	Sub-categories	Meaning Units
Negative emotions	Time frame for adjustment	Taking up to six months to make prosthesis did not help at all; because you don't want to wear dark glasses all the time....(P1)
	insensitive	<p>I think coming here after two days when I was still weak and unwell was a bad idea</p> <p>I think I should have been given more than six weeks counseling; it was nasty of the Trust to have provided me six weeks. I needed more than that...(P2)</p> <p>I don't think my consultant took on board how sick I was; not just my eye; my body was in an ill state; I think that was bad.</p> <p>I think also literally sending me home and say; "take this (conformer) out; clean it without anyone who will teach you properly what to do with it; was really not helping...(P2)</p> <p>If anything comes out of this study you are doing is perhaps; the preparedness about pain... that could be explained to</p>

Category	Sub-categories	Meaning Units
	Lack of support	people ... the immediate care one day; three days after the operation....that was a real shock; really it was....(P3) I lacked family support; I had no where to go for help because I had fallen out with my sister...(P6)
Positive	Relief	Not relevant. I did not have any problems with it because I wanted it taken out...(P7) Nothing really ... because I've never regretted my decision; it was for the best....(P5)

4.3.3.6 Family's adjustment to the loss of vision

Six participants seemed to be happy with their families' adjusting to their loss. Hehir (200:11) maintains that family involvement should be encouraged unless the patient objects to that. Only one participant felt some of her family members did not care at all. However, Tolley and Henninger (1991:19) found that some patients would not rely on family support due to the family members own feelings about the loss of the eye and therefore vision. Basically the family members go through the same emotions as the patients.

Table 4.14 Family and friends' adjustment to loss of vision

Category	Sub-categories	Meaning Units
Positive reactions	Relief	They haven't got a problem...(P1) No problem at all; my wife is happy with everything. I don't regret for what I have done back in 2000.....(P3) My family is now used to it....It is no problem to them....(P1) My husband is brilliant. We just got used to it all now. The impact was that all the time we had to go to the hospital. We can now go on holiday; we can just plan our lives a little bit more; so that's good. My parents are really adjusting to me not being able to see, and that has been brilliant ... I have to say ... I never would have expected it; they've just been excellent...(P2)

- **Counselling**

Out of seven participants five were never referred to counseling. Two had never heard of counseling. One found it irrelevant to her because she wanted the eye to be removed. One did not want to know about it. One would not be bothered. Of the two who were referred; one felt that the sessions were not enough. She suggested that a year's worth of sessions should be given to patients.

The best thing that helped me was the six sessions of counseling that I got with my counselor...that was fantastic. She made me feel solemnly happy....(P2)

This participant is now continuing with her counseling sessions that are offered by services she arranged privately herself.

Another one was referred by her general practitioner to the Crisis Team because she was suicidal. This participant was and still is overwhelmed by the help she received and is continuing with counseling sessions.

Absolutely; meet other patients who had the same operation as soon as possible. They did that with me, and she was reassuring ... that was a great idea.

I would recommend that the hospital organize that ... to build the patients' confidence ... (P2)

- **Contact with another patient**

Five of these participants were never referred to such services. One felt that she would not be bothered to be referred because she would not like to be messed up.

No... not really I wouldn't be bothered about that, I wouldn't like to; I don't want to be messed up....(P4)

Another participant stated that it would be difficult to relate to anybody about this because it was too personal.

I can relate better to her; it would be difficult to talk to anybody about this....it is too personal and private....(P3)

One felt that talking to other people could only be of benefit if people were open and receptive about things.

Sometimes talking to people affects people differently; but I believe that can give help and support especially if people are open and receptive about things.....(P5)

I think if I did have the chance, seen and talked to somebody I would have understood better, I wouldn't have thought of taking my life.(P6)

Out of the five who were not referred three agreed that, the service could help people to get things out of their chests and it could have made a huge difference if it was offered in the first place.

Although I was never offered that service ... I think it would be a good idea to have someone who had the same operation as you ... to talk to you about the operation

- **Practical advice/help**

Timeframe: One participant expressed that he didn't have enough information as to how long exactly he would be going around without a proper prosthesis and wearing dark glasses. He found six months quite long and unacceptable.

I think it would have been very helpful for the people to have a better idea of ... in particular the one that they would be going about the first six months without a proper prosthesis and wearing dark glasses...(P1)

Trial run on using conformer: Two participants raised the problem of fitting the conformer on and taking it off. They both needed to be prepared for that before they left the hospital. One indicated that he had shaky hands and it was difficult to handle that on his own.

Perhaps a trial run of changing the plastic shell (Conformer) before you leave the hospital....Taking it in and out was a nightmare especially if you have shaky hands like me.....(P1)

One was quite emotional about inserting a conformer, she indicated that feeling that “hard thing” hit her, she came to a realization that she was not going to see again in that eye; it felt strange and weird.

Preparedness prior to surgery: One participant reported that he was never given enough information about how he would feel after his surgery. The pain he had was unbearable and felt that could be the time he would have been offered counseling and emotional support for his pain management.

Trying to prepare...prepare people. Preparing people about what is going to happen is the only thing that let me down. “Pain following the operation.” Preparing the family members about what to expect as they will help the patient with care. (P3)

Doctors should ensure that the patient gets enough pain relief before and after surgery.(P2)

Secondly, he thought it would be advisable that the family was involved and prepared for what to expect as far as the socket is concerned, because his wife was so shocked that she nearly fainted.

My wife almost fainted because she wasn't prepared for that before hand (P3)

Piff (1998:13-14) maintains that sensitivity to family members is important. Nurses should not assume that the family can cope, because families are usually terrified by the surgery as well.

I didn't get support following my surgery ...I am not sure whether the reason may be the lack of skills and expertise to sort of handle post-operative issues....the GP's are able to cope with patients with broken arm; but they would probably be unable to cope with someone who had his eye removed.

Aftercare: Two participants felt aftercare was lacking. One felt the health professionals gave first preference to dying patients other than the blind or partially sighted.

Hospital aftercare following the operation is a point of departure. I think health professionals give the people who are dying first preference than they do with the blind or partially blind; especially those who have lost their eyes....(P6)

One felt there was no continuation of care from the hospital.

Independence: Donnelly (1987:55) in her study found that problems concerned with independence in the home were the main reason for requesting for practical help. One participant was very angry that she had not received any help concerning proper accommodation as her movements were restricted since she lost her eye. This participant had no idea who to consult, the doctors or the council.

I don't see well ... I live in a three bed room house upstairs... I need a smaller house where I can be able to go around by myself, but the Local Council has not yet provided me with a safe house. The doctors did not refer me to the Local Council so that I can get a better accommodation....(P4)

Nurses: One participant felt that the nurses needed some training to be able to deal with the patients who were in such a situation. The nurses had to learn to respect the patients' privacy and they also needed to understand the emotional impact of eye surgery. Piff (1986: 16) emphasized the need for the maintenance of absolute privacy by the nursing staff. Tolley and Henninger (1991:19) found that many ophthalmic nurses, though empathetic, were unprepared to deal with the emotional needs of patients who had enucleation or evisceration.

I think it would have been very helpful for the people to have a better idea of ... in particular the one that they would be going about the first six months without a proper prosthesis and wearing dark glasses...(P1)

Further, Clarke and Wyn-Williams (2000:17) identified the problems as lack of training of nurses in psychosocial issues.

Doctors: One participant felt the doctors did not give enough information about the reason for the eye operation. The doctors did not avail themselves during the time of crisis. There was a need for patients to be properly referred for counseling for longer sessions than six months. Tolley and Henninger (1991:19) found that some ophthalmologists were reluctant to refer their patients to external resources. The authors also reported on the need for family members to be involved in the care of the patients and adequate pain control.

In this study the doctors were also found lacking in determining the impact of the diagnosis on the patients.

I wasn't fit to come in ... but I remember I was an emotional wreck ... I was sitting there at the waiting room crying my eyes out. I just bawled ... I don't think the consultant was prepared for the emotional side of things ... he didn't realize that I have been affected ... (P2)

Written information: One participant felt that written information in the form of pamphlets, leaflets and books on the subject would be appropriate to prepare patients prior to surgery as well after the event.

Not much information was given to me on what to expect before and after my operation. I felt let down...(P6)

I also think there should be books; leaflets; pamphlets on the subject ... that would be helpful to people who have been through the same experiences as mine ...(P6)

4.4 CONCLUSION

In this chapter the findings and results were discussed. The meaning units that supported the themes, categories and subcategories were included. The discussions were based on supportive literature. Chapter 5 discusses the conclusions and recommendations.

CHAPTER 5

Conclusions, recommendations and limitations

5.1 INTRODUCTION

In this chapter the major research findings as presented in the previous chapter are highlighted. The recommendations based on the findings of the study are also presented.

The purpose of this study was to gain understanding into the emotional experiences of patients who had undergone removal of an eye so that care of these patients could in future be holistic in relation to addressing their emotional needs and assisting them to cope with their loss. The main objective was to explore and describe the emotional experiences of patients following the removal of an eye through enucleation and evisceration.

An exploratory and descriptive design was used to explore the emotional experiences of patients who had an eye removed. A qualitative research approach was used to conduct an in-depth conversational interview with those patients who had undergone enucleation or evisceration. An interview guide that had one core question to start the conversation was used and probing questions emerged directed by the conversation. The core question stated: **“Tell me about your feelings, emotions and experiences following the eye operation you had. You can start from the time you were told that you had an eye condition that may require that the eye be removed”**. Structured interview format was used to collect biographical data.

The conversational interviews were conducted in a private office specifically identified for the purpose at The Queen Victoria National Health Services (NHS) Foundation Trust in the Corneo-Plastic Unit (CPU). The interviews took place per appointment at the time the patients had come for their follow-up clinic appointments.

5.2 MAJOR FINDINGS

The findings of the research were based on the objective. Data obtained expresses the feelings and emotional experiences following removal of an eye as expressed by participants in relation to self, family and friends.

After a rigorous analysis of data emanating from the participants, narratives regarding their feelings, emotions and experiences following removal of an eye were given meaning.

5.2.1 Biographical data

All participants were adults with age ranging between 31 and 61, living with a relative/s or relation. Even though five were unemployed only two did not have access to benefits. Gender distribution was fair, four (4) females and three (3) males (see table 4.1).

5.2.2 History of eye problems resulting in enucleation or evisceration

The findings of the study reflect that all the participants had different underlying ocular diseases responsible for the painful eye leading to enucleation or evisceration. These included congenital or acquired glaucoma, microphthalmus, buphthalmus, endophthalmitis, Stevens Johnson Syndrome, Riley Day Syndrome and trauma. Of all these conditions the common problems were pain and poor or no vision.

5.2.3 Feelings and emotions following removal of the eye

5.2.3.1 Negative emotions

Being told that you are going to lose an eye is a traumatic event. According to the findings in this study, participants even those who had requested the operation, were shocked when it was confirmed that the operation will go on and they will after all loose the eye. *Well I wanted it done ... I just expected that it was a big step and irreversible ... (P2)*. According to their responses in tables 4.3 and 4.5, they experienced a sense of loss and despair. There was nervousness, panic and apprehension that soon turned to anger, desperation, tension, depression, self reproach, guilt, doubt, even disbelief and denial for some. The emotions were so intense that P2 thought that she was loosing her mind *I was getting hallucinations. I don't know what hallucinations are ... but I was told that I am hallucinating ... I thought it might be septicaemia ... I wanted someone to explain to me ... because I thought I was going mad ... I was just seeing things ... I wanted to know why I am seeing things ... why I am imagining things and panicking ... I wanted to know ... why I am seeing things ... why am I kind of acting a bit mad.*

This participant was emotional even as she was conversing about this.

I remember clutching my head just to let a silent scream ... I'm going ...no ...oh! ... and just begging. I was so shocked ... I remember sh ... shaking (P2).

One other participant was angry at self as well as the doctor *I was angry at myself ... angry at the doctor.*

For some there was doubt and confusion. This was expressed in the mixed feelings that were stated by (P4) *I had mixed feelings ... I felt bad that part of me would go missing ... but I also knew that I would no longer have pain ...the news still shocked and scared me...*

I was cross ... I was confused ... I didn't want to do it ...but I needed it done... (P6).

A response of mixed emotions was evidenced by P5 where she earlier reported fear *I think I was probably ... a bit apprehensive and scared ... Eh ... Yes ... I was absolutely scared ...* The same participant later reported *I was laughing and giggling all the way to the operating theatre...I am a very strong person ...*

According to Crossland and Culham (2000:21) these responses are necessary when one is in a crisis, because they are a manifestation of a basic psychological defence mechanism for survival and even though transient, many of these emotions reappear at different times. The emotions are normal and are an attempt to understand the loss and they are therefore not to be discouraged, but to be managed, hence this study.

According to the findings of this study, these emotions are experienced before and after the operation. The only difference is that they should be put in the correct context. Of importance are the expectations post operatively. For some participants there was disappointment especially in relation to pain *I thought the pain will stop but it hasn't ... I am a bit disappointed (P1).*

I am still fed up ... I still have pain and am unable to work because of it ... life has been put on hold ... I can't work again. When ... you got ambitions and can't do what you wished for, is bad ... (P1).

No ... I have not found the operation valuable ... (P4).

5.2.3.2 *Positive emotions*

In the findings of this study, there were participants who were positive about the outcomes. These participants weighed the gains of losing the eye against their quality of life. For them losing sight posed a new challenge they were prepared to face because according to literature and the history on the reasons for the operation, the eye that is removed usually has poor or no vision and it is painful. Participants in this study reported:

I requested it ... Yes ... many years of pain, socially isolated and just coping with life ... I had had enough ... (P7).

I asked them to get rid of it ... I wanted to cut my losses ... and just have the operation (5).

5.2.4 **Facial appearance**

5.2.4.1 *Negative emotions*

Post operatively the negative emotions were also related to the way the socket looked, the fit of the artificial eye and the care that goes with it. For some the appearance was not acceptable. *The bottom part of my eyelid has become sunken ... and I believe this can disrupt you false eye ...it can actually fall out ... and it did fall out ... that was embarrassing ... (P3).*

5.2.4.2 *Positive emotions*

Participant No.5 was lucky *Wonderful! I wish I had done it earlier because there was hardly any vision in that eye anyway*

5.2.5 **Aspects that contributed to these feelings and emotions**

5.2.5.1 *Information communicated to patients in terms of reasons given for the eye operation*

According to the findings of this study, participants were not, in the first instance, given adequate and/or relevant information about the diagnosis and secondly about the operation. The little information given was either technical or insensitive and it was given at the time the patient

was not ready for it ... *I wasn't actually shown pictures, or people who had an artificial eye ... I didn't realize that there will be a problem with eye movement... (P1).*

I don't think he explained to me to understand ... my knowledge of understanding was not clear ... he did not ... simply ... some things were technical ...

No ... I think at the time ... that's all he should have given me because I was in such a shock ... but I think I should have been given much information between that point and when the eye was actually removed because I had to wait a day... my consultant ... I didn't see him again ... I desperately wanted to speak to him more, because I trusted him ...(P2).

According to the participant she did not comprehend anything said because she was still shocked. Seemingly, according to the hospital, that was the only information that she was to receive or time that was going to be spent with her. She felt the surgeon did not have time for her.

Aspects of insensitivity were evidenced in this quote *Basically he just sort of said ... eh ... I think it was the only way to say ... He just said straight out " we are going to have to remove the eye because the infection is so bad" In a way it was of the best but it was brutal ...(P2)*

According to this participant the surgeon did not find a more humane way of putting it.

5.2.5.2 Questions asked by patients

From the findings of this study pain rated high in the minds of all participants and it was one of the main reasons all of them agreed to enucleation or evisceration. Before operation, participants (as patients) had asked about pain post operatively, whether this will be relieved or not. They had asked about the procedure how it will be performed, duration, its impact on the other structures of the eye like tear ducts, the impact on the remaining eye, recovery time, costs, disfigurement and impact on quality of life including daily activities. Participants wanted to know about issues of interaction where the eye plays such an important role. According to Hehir (2000:10), it is not unusual for patients to express fear of "having a hole" where the eye was. All the participants wanted to know about the socket, they wanted reassurance about the artificial eye- will the socket be an empty hole? How will it look like? Will the artificial eye look like the other eye? Will it fit properly? Will it be noticeable to other people?. ...*will people notice that I haven't got*

an eye?... will I look different?... These are pertinent questions which if effectively addressed would prepare patients better for the loss of an eye.

According to the findings herein there was information gap as there were no specific responses given. The participants reported not even having information leaflets that they could refer to. One participant reported her concerns about the care of the artificial eye *Perhaps a trial run of changing the plastic shell before you leave the hospital ... taking it in and out was a nightmare especially if you have shaky hands like me ... (P1).*

5.2.6 Reactions of self, family and friends post-operatively

- **SELF**

Five of the participants (P1,2,3,4,6) had a big shock when they saw the socket moreover the area around the eye was bruised. One of them went into a deep depression. *I feel very depressed at times ... I believe I would be better if I would come off anti-depressants ... I mean I am ok when I take them ... when I stop I fall back into depression...(P2).*

It's a big shock ... isn't it? I had been expecting it. I was prepared for ... but it was a big shock ... you loose something that you had all you life and it's gone ... and that was really ... a ...sh ...(P1).

I didn't want to speak to anyone ... I just couldn't believe of what had happened to me ... I wasn't myself ... (P2).

One participant did not feel comfortable with the husband. *Well with my husband ...I felt weird around him ... I still do not feel myself with him ... I'd rather he did not look at my eyes sometimes*

One participant's disbelief and disfigurement was so great that she did not want to recognize herself as such. *at first as I was looking into the mirror I didn't like it ... it was not me ... (P6).*

Positive reactions were from P4 and P5.

I am glad that it is done because at least it looks like an eye and I have no pain ... (P4).

After three months I was not thinking about it at all, I was looking forward to having a prosthesis ... (P5).

- **Family's reaction to removal of an eye**

The reaction of family was similar to that of the individual. Shock was still marked as the initial reaction. *My mother was so shocked she kept on saying ... isn't that dreadful ... My sisters pretended they haven't noticed ... my little nephews and nieces noticed and asked to look under my darkglasses.... (P2).*

The most traumatic experience my wife had was when they removed the bandage ... she almost fainted when she saw my socket because she was not prepared for that ... (P3).

For those families that had been with the participant experiencing his/her suffering the reaction was that of relief. *Nothing too shocking, I mean they sort of went on with the job ... and they weren't disgusted or shocked by it really. They were happy that it was looking healthier ... (P5).*

Some family members concealed their reactions such that the participant was not able to identify these. The families that were angry blamed the participant for making the decision to have the eye removed. *They were so ... o angry! That's all I could describe ... they were all so angry ... My mother ... the first day she was in shock ... second day ... she started saying ... how could this happen? (P2).*

5.3 CONCLUSIONS ABOUT THE FINDINGS

Great volumes of pertinent data was collected from the seven participants that took part in the study. Participants were concerned about their quality of life. From the findings it can be concluded that:

- Enucleation and evisceration are psychologically and emotionally traumatic events to patients. Patients experience a deep sense of loss that is irreversible. The loss is final and is similar to death. Patients therefore go through all the stages that a person with a terminal disease would go through. In the case of patients who have lost an eye the issue is complicated by the fact that the patient is not dying. Life must go on. The fact that

there may be another eye is no consolation. To this effect Partridge (1997:186) contends that in enucleation the initial shock associated with a sudden change in appearance can develop into a longer sense of bereavement as it gradually becomes apparent that the disfigurement is for life and no medicine will bring a cure to it. Patients experience shock, anxiety, fear, devastation, depression, denial, anger, guilt, self reproach and when the eye has been removed, over and above these emotions is the issue of coping with disfigurement and the stigma that impact on the self like self image, self consciousness and self esteem. According to De Leo et al (1999:339) these emotions usually occur simultaneously, may recur and persist overtime. Crossland and Culham (2000:21) report on these emotions having a negative impact on relationships with the significant others. This was confirmed by one of the participants' response ... *I was angry at my doctor ...at myself.* Another participant reported that she was very depressed and this did not help her relations with her sister *this is the period that my sis and I had a physical row ... it was so bad that I went into depression, I did not want to talk to anybody ... I became suicidal ... I was wondering if I did the correct thing, I just could not cope ... (P6).*

- Patients who underwent enucleation or evisceration at The Queen Victoria National Health Services (NHS) Foundation Trust in the Corneo-Plastic Unit were, at the time of investigation, not adequately psychologically prepared to cope with the challenge of losing an eye. They did not get adequate information that would equip them for the outcomes. There were no pamphlets that patients and their families could read and refer to should they so wish. The professional staff were very busy and at any rate patients thought that professionals in the hospital were not prepared to engage on psychological and emotional issues with patients ... *I wasn't fit to come in ... but I remember I was an emotional wreck ... I was sitting there at the waiting room crying my eyes out. I just bawled ... I don't think the consultant was prepared for the emotional side of things; he didn't realize that I have been affected. (P2).*

Information, if appropriate and correctly disseminated is a powerful tool for support. To this effect Sen (2005:1) has reported that in health care facilities many patients' anxieties might be allayed by providing basic information like, what to expect, nature of the procedure, who is involved, where, when and what will be required or expected of the patient. This was supported by the nature of questions that participants had put to health professionals, like, presence of pain following the operation? How will the eye be taken out? What impact will the operation have on

the tear duct? Duration of the procedure? How soon will the artificial eye be fitted? What is the recovery time? There was no indication from the participants that these questions were addressed.

- As a result of patients not being emotionally and psychologically prepared; their families were also not prepared and were therefore not able to provide the emotional support they were expected to give at the time this was needed most. According to the findings of this study, family members went through the same emotional feelings as the patient usually at the same time as the patient did. The example here was the wife who collapsed when the bandage was removed. Probably this was the first time for the patient also to see the socket as well.
- Another finding was about the health professionals. Literature according to Tolley and Henninger (1991:18) has reported nurses to be under prepared to provide emotional support to patients in crisis. In this study, in line with this finding only two nurses were reported to be empathic. Participants were supportive of nurses being trained in this area. Because of the nurses' lack of knowledge in this area, most of the participants received the information from the physicians, which information was also reported inadequate, technical and sometimes insensitive.

5.4 RECOMMENDATIONS AS OUTLINED BY PARTICIPANTS

The objective of this study was to explore and describe the emotional experiences of patients following the removal of the eye through enucleation and evisceration with the aim of providing emotional support to patients before, during and after eye operations particularly enucleation and evisceration. Data collected has provided the lived experiences and emotions of the affected patients and has provided a basis to design training protocols for health care professionals particularly in The Queen Victoria National Health Service (NHS) Foundation Trust. The recommendations are deduced from the participant's responses. They are also extracted from the questions participants stated to have asked as well as stipulations on what assisted or did not assist them to adjust to their plight.

5.4.1 Training of professionals

Participants recommended that a programme be designed for health professionals to be trained in the counselling of potential clients for evisceration and enucleation. The content could be based on seeking responses to the questions relating to pain, the nature of the procedure, audio tapes for sounds during operation, duration of the operation, impact of the operation on the remaining eye, recovery time, the prosthesis, how to care for it, how to fit it on and remove it, appearance immediately and subsequently after the operation, how to handle curious bystanders, how to relate to irate family and non-supportive family members. Picture albums, video tapes and demonstrations of activities that the patient needs to perform will be very helpful.

Patients to be operated upon should be admitted days in advance and undergo training by a professional psychologist on how to express and manage emotions related to the planned management of their condition.

Patients should be shown all patterns of artificial eyes and allowed to make an input into the type and colour of prosthesis to be fitted on. They should be made to touch and feel them and afforded a chance to practice on how to fit them on and take them off under supervision. This would make them feel involved in the process and would also give them the confidence in handling the prosthesis. The exercise would also give them a chance to affirm their decision and accept the fate thereof. This was a firm recommendation of one of the participants.

I would recommend that the hospital organise that ... to build the patient's confidence (P2).

To address the immediate needs in the Queen Victoria National Health Foundation Trust, Corneo Plastic Unit, an in-service training course which can help the nurses develop a better understanding of how it feels to lose one's eye and sight and emotional problems created by visual impairment and how to manage these, should be instituted as a matter of urgency. The programme should be based on managing patients in crisis and should include aspects of interpersonal skills.

5.4.2 Support therapy group

Support therapy groups and networks should be formed within the hospital and outside where patients, about to undergo enucleation or evisceration, can be referred for counseling by persons

who have experienced what they are about to experience. This has also been recommended by participants.

Absolutely meet other patients who had the same operation as soon as possible ... they did that with me, and she was reassuring ... that was a great idea.

I think if I did have the chance, seen and talked to somebody I would have understood better, I wouldn't have thought of taking my life (P6)

5.4.3 Information brochure

Some of the content of this brochure has already been outlined by participants in the responses on “what helped or did not help in adjusting to your loss”. More information could be on the anatomy and physiology of the eye, the impact of pathology, alternative management strategies, the procedure on enucleation, evisceration and exenteration, preparation for hospitalization including what is expected of the patient in the process. However information must be properly presented and edited and must avoid unrealistic outcomes. Patients can then take this home, share with the family and internalise the content thereof.

5.4.4 Attention to human resources

The hospital teams must be multidisciplinary in composition and ensure that psycho-social specialists are included in the team.

Due to the role ophthalmic nurses play in the core team, the delicate structure of the eye and the importance of the function of the eye, formal training of nurse specialists on emotional support of patients who are treated for both medical and surgical eye problems should be supported. This should be done firstly at local and national level and secondly, worldwide so that ophthalmic nurses employed in eye units have the necessary proficiency.

5.5 RECOMMENDATIONS FOR FURTHER RESEARCH

In line with the findings in this study, it is recommended that a study to explore the nurses' knowledge in the psychological and emotional management of patients in crisis be conducted. The nurse training curricula can also be reviewed to evaluate the inclusion and adequacy of content in this area. The findings from such a study may be helpful in compiling training manuals starting from the known to the unknown.

5.6 LIMITATIONS OF THE STUDY

- **Timeframe**

There was a delay in processing of the proposal because the study was conducted in the United Kingdom where ethical issues when dealing with human subjects have to be attended to through a lengthy and elaborate process before the proposal can be accepted, even though the University of South Africa had accepted the proposal. Therefore in line with the timeframe for the completion of the study data collection was delayed impacting negatively on the duration of the study.

- **Situational contaminants**

Although an office away from the busy part of the unit was allocated for interviews and a note was displayed to '**not to disturb**', the noise was not completely shut out. This tended to lengthen the time of the interviews as in some instances interviews had to be stopped momentarily until the noise subsided and/or questions had to be repeated due to poor audibility.

- **Generalisability of findings**

The findings of the study cannot be generalised to a larger population because data was collected from a few participants and a small sample size does not permit firm conclusions. The study can be replicated in similar situations.

The research was only conducted to include patients who had removal of an eye through enucleation and evisceration. It is not known whether patients who had lost an eye through exenteration and those who lost sight through disease encounter similar or different challenges.

5.7 CONCLUSION

Although a small sample size does not permit firm conclusions, fundamentally these findings suggest that loss of an eye and sight can induce severe emotional outbursts in patients regardless of whether eye surgery was requested or not. It is evident from this study that most participants, and therefore patients with problems requiring enucleation or evisceration in Queen Victoria Hospital NHS Foundation Trust do not receive satisfactory pre and post operative emotional

preparation and emotional care. In the study these patients were often left to adapt on their own; and although most eventually succeeded, it is obvious that they go through a very difficult time.

The results of this study were supported by studies undertaken by most of the researchers who stated that the emotions and feelings of patients who lost vision through enucleation or evisceration tended to be overlooked and under treated (Coday et al 2002:3). The findings emerging from this study clearly stress the need for greater sensitisation to feelings and emotional well being of these patients.

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APPENDIX: A

DATA COLLECTION TOOL

**THE EMOTIONAL EXPERIENCES OF PATIENTS FOLLOWING
REMOVAL OF THE EY (ENULCEATION OR EVISCERATION)**

SECTION A: BIOGRAPHICAL DATA

NB. The information for SECTION A will be retrieved from the patient's records.

1. AGE

21-30	
31-40	
41-50	
51-60	
61 AND ABOVE	

2. GENDER

MALE	
FEMALE	

3. MARITAL STATUSES

SINGLE	
MARRIED	
CO-HABITING	
SEPARATED	
DIVORCED	
WIDOWED	

4. DO YOU LIVE?

ALONE	
OTHERS	

Specify.....

5. EMPLOYMENT STATUS

EMPLOYED	
UNEMPLOYED	
UNEMPLOYED WITH BENEFITS	
SELF-EMPLOYED	
HOUSEWIFE	
RETIRED	
OTHER	

Specify.....

6. Year and date of the operation?

.....

SECTION B

7. THE INITIAL INTERVIEW GUIDE

Aim: To determine the emotional status of the patient after removal of the eye through Enucleation or Evisceration. A core question will be asked and the rest of the questions are possible probing questions

7.1 FEELINGS (EXPERIENCES)

7.1.1 CORE QUESTION:

TELL ME ABOUT YOUR FEELINGS, EMOTIONS AND EXPERIENCES FOLLOWING THE OPERATION YOU HAD. YOU CAN START FROM THE TIME YOU WERE TOLD THAT YOU HAVE AN EYE CONDITION THAT MAY REQUIRE THAT THE EYE BE REMOVED.

7.1.1.1 POSSIBLE PROBING QUESTIONS ON FEELINGS, EMOTIONS AND EXPERIENCES

7.1.1.1.1 Before your eye was removed did you have any problems with your eyes?

.....

7.1.1.1.2 What were your feelings at the point of being told that your eye will be removed?

.....

7.1.1.1.3 How did you feel about the reason you were given for the removal of your eye?

.....

7.1.1.1.4 How did you feel about the information you were given relating to your surgery?

.....

How was it presented to you?

.....

And what was your response?

.....

7.1.1.1.5 To what extent was the information valuable to you?

What information did you find helpful?

.....

7.1.1.1.6 what questions did you ask or have in mind concerning your proposed surgery?

.....

7.1.1.1.7 How did you feel immediately after your eye was removed? (The first 24 hours).

.....

How do you feel now?

.....

7.1.1.1.8 Was there a change in a week, 4-6 weeks, 3 months, 6 months, 1 year later?

 7.1.1.1.9 How did your family respond to hearing the news that the management
 Of your eye condition is removal of the eye?

 How did they feel then?

 How do they feel now?

7.1.1.2: POSSIBLE PROBING QUESTIONS ON APPEARANCE

7.1.1.2.1 How did you feel when you saw your eye socket for the first time?

 Was it what you expected?

 7.1.1.2.2 How soon after your surgery did you receive your artificial eye?

 7.1.1.2.3 What was your initial feeling after your artificial eye was fitted?

 Were you satisfied with it?

7.1.1.2.4 When you looked at your face and the eyelids was there any change in your
 appearance? And if so: in which way?

7.1.1.2.5 Did you show your family members your eye socket immediately?

 7.1.1.2.5 What was your family's reaction when they saw your eye socket for the first time?

7.1.1.3. POSSIBLE PROBING QUESTIONS ON ADJUSTING TO VISUAL LOSS/SUPPORT

7.1.1.3.1 What things do you find difficult in adjusting to the absence of the eye
 In relation to:

- Yourself? How do you feel about yourself? (Self-identity/ Self-image)

- Your family/friends

- Relationship with society

7.1.1.3.2 What helped you adjust to the loss of your eye in relation to?
 (Self, family, friends, health professionals, voluntary organisations,
 Others) who in particular helped you go through this difficult time?

7.1.1.3.3 What did not help you in adjusting to the loss of your eye?

7.1.1.3.4 How is your family adjusting to the loss of your eye now?

7.1.1.3.4 What would you suggest that the professional staff should do to help?
You overcome the feelings you have/had following the removal of
your eye? (For example: Counselling, Contact with another patient,
Practical advice)

.....

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APPENDIX: B

Invitation to take part in research study: The Emotional Experiences of Patients following Removal of the Eye (Enucleation or Evisceration)

Dear Participant,

I am undertaking a research study to explore the emotions, feelings and experiences of people who have had an eye removed. This research is being carried out as part of an educational qualification for MA degree.

This leaflet sets out to explain why you have been invited to take part, what you will be asked to do and the disadvantages, risks and benefits of participation. Please take the time to read it. You are welcome to share the contents and discuss them with your friends and family. If you find anything unclear, or would like more information, please contact me. My details are at the end of the leaflet.

Why have you been asked to participate?

Your participation is very important to this study. I should like to use your experiences to assist me and other nurses and healthcare professionals to provide better and more appropriate care to others who will be undergoing a similar operation in the future.

What will you have to do?

I have prepared some questions to ask you to find out how you felt about the diagnosis, what plan of management was agreed and how you felt after the operation. The discussion will take about 45 to 60 minutes.

You will not need to make a separate appointment as these questions can be asked when you come for your follow-up appointment. I will agree the date and time with you. I may ask you if you mind my using a tape recorder during your discussions and I will only use it with your permission.

It is to make sure that I have an accurate record of my conversations with you. I may also ask to have a look at your medical records. You do not have to give permission if you do not wish to do so.

Please let me know if you would not be happy to receive a follow up telephone call from me within the next two weeks after our conversation to clarify your comments.

Confidentiality

Our discussion will take place in a separate private room where there will be no disturbances. All information collected by me will be totally confidential and your name will not appear in any reports or documents.

The tapes will be destroyed once the study is completed after nine months. Any recording made will be kept until the completion of the study. With your permission tapes may be passed to an experienced audio-typist for typing.

What risks and disadvantages are there?

There are no known risks from taking part in this study. However, you may find it unsettling to talk about your emotions and feelings. If you feel at any time that you do not want to continue the discussion, please say so. If you would like support or counselling, staff will be available. Please see the end of this leaflet for details.

What benefits are there?

There is no financial gain for taking part in this study. However, there are three possible benefits:

1. You may find it therapeutic to be able to express your feelings about the surgery and the nursing care and what it meant to you.
2. Health care professionals will be able to learn from your experiences and improve their professional practice.
3. Future patients will benefit from this improvement in professional practice.

What do you do now?

If you would like to take part in the study outlined above, you will be asked to sign a consent form, a copy of which will be given to you to keep.

Please note that this agreement is not binding and that you will be free to withdraw at any stage during the study if you should wish to do so. I will ask you to agree a date and time for the discussions with me and, with your permission, I will let your GP know that you are taking part in this study.

Your treatment or relations with the health care team will not be affected if you decide not to participate or decide to withdraw at a later stage.

Should you have any complaints or concerns about any aspects of the study please contact the complaints manager. See details below.

CONTACTS

Researcher

Rose-Mercy Dikeledi Tlale (Registered Eye Nurse)
Corneo-Plastic and Oculo-Plastic Unit
Queen Victoria Hospital NHS Foundation Trust
Holtye Road
East Grinstead
West Sussex
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Tel: 01342 414466/414470

Counsellor and Emotional Support Therapist

Mrs Theresa Rose
Queen Victoria Hospital NHS Foundation Trust
Holtye Road
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Tel: 01342 414478

Complaints Manager

Mrs Debby Weller
Queen Victoria Hospital NHS Foundation Trust
Holtye Road
East Grinstead
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Tel: 01342 414355

If you would like a large print copy of this leaflet, please contact me at the above address.

Thank you for your time
Rose Tlale (Researcher)
Date: 22 August 2006

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Consultant Ophthalmologist and Oculoplastic Surgeon

Direct Fax No: 01342 414106

APPENDIX: B

Dear Participant,

Re: Invitation to participate in the current study on: **The emotional Experiences of Patients following Removal of the Eye**

You are invited to participate in the above mentioned study that will be conducted at Queen Victoria NHS Foundation Trust in the Corneo-Plastic Unit by one of the nurses Rose Tlale.

In your participation, Rose will initiate a conversation with you by asking you to share with her your feelings about losing an eye and continued problems you have from the time the diagnosis was made.

An information sheet is attached. Please read this and should you have any questions about the study do not hesitate to contact Rose Tlale.

There will be no bodily invasion and the conversation which will take a form of an interview will last for 30-45 minutes.

An Addressed envelope with a valid postage stamp is enclosed should you want to respond.

Rose Tlale will be contacted at the following numbers:

01342 414470/414466 (Work)

01342 311572 (Home)

07754835101 (Mobile)

Yours Truly

Rose Tlale

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CORNEO-PLASTIC UNIT & EYE BANK

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APPENDIX: C

Patient number: _____

PATIENT CONSENT FORM

Title: The emotional experiences of patients following removal of the
Eye (Enucleation or Evisceration): Qualitative Study

Researcher: Rose-Mercy Dikeledi Tlale (Ophthalmic Nurse)
Corneo-Plastic Unit
Queen Victoria Hospital NHS Foundation Trust,
Holtye Rd East Grinstead, RH19 3DZ

SIGNATURE

1. I confirm that I have read and I understand the information sheet for the above study and have had the opportunity to ask questions.
2. I understand that my participation is voluntary and that I am free to withdraw at any time, without giving any reason, without my medical care or legal rights being affected.
3. I understand that my GP must be informed of my participation in this study, and I give consent for that to occur.

By signing below, I voluntarily agree to take part in this study.

4. I agree to the interview consultation being audio-taped.
5. I agree to the use of anonymised quotes in publication.

Name of Patient:	
Signature of Patient:	
Date:	
Name of Investigator:	
Signature of Investigator:	
Date:	

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10 February, 2006

CORNEO-PLASTIC UNIT & EYE BANK

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APPENDIX: D

Mrs LV. Monareng
Department of Health Studies
University of South Africa
P.O Box 392
Unisa
0003
Republic of South Africa

**PERMISSION TO CONDUCT RESEARCH FROM THE RESEARCH & ETHICS
COMMITTEE: UNIVERSITY OF SOUTH AFRICA**

Dear Mrs Monareng,

I hereby wish to apply for a letter of consent from the Ethics Committee to conduct research. The Queen Victoria Hospital NHS Foundation Trust has requested such a letter before they can give me permission to conduct my research on: The emotional experiences of patients following removal of an eye (Enucleation or Evisceration). I contacted Mrs Sarah Dawe and she suggested requesting such a letter from you.

Thanking you in advance
Rose-Mercy Dikeledi Tlale
Registered
Ophthalmic Nurse/Researcher

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Sarah Dawe (QVH Research & Development Committee)

APPENDIX: D

RE: ROSE-MERCY DIKELEDI TLALE'S COMPLETION OF MASTER OF ARTS IN NURSING SCIENCE PROGRAMME THEORY AND EMBARKING ON DISSERTATION WITH THE UNIVERSITY OF SOUTH AFRICA

Dear Madam,

I hereby wish to make madam aware of the fact that my University requires me to undertake a Dissertation on the topic chosen by me from the unit I am presently working.

The study will be conducted on the patients who will be willing to participate.

I have started a long distance short course on Ophthalmology with the University Aberdeen, no attendance required. This will help me in the study I am about to embark on. I am required to work on small projects and case studies on the patients that I nurse and are seen in the clinic.

I intend to go through the correct channels, i.e., ask permission from Mr Daya, Mr Malhotra, Mrs Becher & the QVH Research Committee, to be able to access to the patients files during the period of my study.

My topic is: The emotional experiences of patients following removal of the eye (Enucleation/Evisceration)

I hope to explore and describe the emotional experiences of patients following removal of an eye through enucleation and evisceration.

I will from time to time inform madam of all my actions and achievements.

I intend to use my off duty, Annual Leave and I will be paying for my tuition and books
Thanking you in advance.

I am.

Rose-Mercy Dikeledi Tlale.

Queen Victoria Hospital 
NHS Foundation Trust

Holtye Road
East Grinstead
West Sussex
RH19 3DZ
Telephone: 01342 414000
Safe Haven Facsimile: 01342 414113
01 June, 2005

CORNEO-PLASTIC UNIT & EYE BANK

Sheraz M. Daya, MD,FACP,FACS, FRCS (Ed)
Director & Consultant Ophthalmic Surgeon
Raman Malhotra FRCOphth
Consultant Ophthalmologist and Oculoplastic Surgeon

Direct Fax No: 01342 414106

Mrs C. Becher (Director of Nursing)

APPENDIX: D

**RE: DIKELEDI ROSE-MERCY TLALE DISSERTATION & CASE STUDIES
ON PATIENTS IN THE UNIT & CLINIC**

Dear Madam,

I have completed my Master of Arts in Health Studies (Theory) with the University of South Africa and I am required to undertake a research study on a topic chosen by me from the Unit I am presently working in. I therefore, ask for permission to undertake a study on some of your patients in Corneo Plastic unit. I have written to my Ward Manager, Mr Malhotra & Mr Daya, Oculo-Plastic & Corneo-Plastic Unit respectively.

The theme of my study is: The emotional experiences of patients following removal of an eye (Enucleation/Evisceration).

My objective:

- To explore and describe the emotional experiences of patients following removal of an eye.

I have taken a long distance short course (Degree) in Ophthalmology with the University of Aberdeen (2005-2006) that I believe will be beneficial on this study. No attendance is required. I intend to embark on case studies and projects that will help the unit and members in the provision of safe care.

I intend to use my off duty and annual leave time to undertake my study. At the present moment I am collecting appropriate material to base my study on and I will notify you of my achievements during the course of the year. I will also be responsible for my tuition and study material.

Thanking you in advance.

I am,

Rose-Mercy

Dikeledi Tlale

(Researcher)

East Grinstead
West Sussex
RH19 3DZ

Telephone: 01342 414000
Safe Haven Facsimile: 01342 414113

CORNEO-PLASTIC UNIT & EYE BANK

Sheraz M. Daya, MD,FACP,FACS, FRCS (Ed)
Director & Consultant Ophthalmic Surgeon

Raman Malhotra FRCOphth
Consultant Ophthalmologist and Oculoplastic Surgeon

Direct Fax No: 01342 414106

Ward Manager,

APPENDIX: D

RE: ROSE-MERCY DIKELEDI TLALE'S COMPLETION OF MASTER OF ARTS IN NURSING SCIENCE PROGRAMME THEORY AND EMBARKING ON DISSERTATION WITH THE UNIVERSITY OF SOUTH AFRICA

Dear Sir,

I hereby wish to make madam aware of the fact that my University requires me to undertake a Dissertation on the topic chosen by me from the unit I am presently working. The study will be conducted on the patients who will be willing to participate.

I have started a long distance short course on Ophthalmology with the University Aberdeen, no attendance required. This will help me in the study I am about to embark on. I am required to work on small projects and case studies on the patients that I nurse and are seen in the clinic.

I intend to go through the correct channels, i.e., ask permission from Mr Daya, Mr Malhotra, Mrs Becher & the QVH Research Committee, to be able to access to the patients files during the period of my study.

My topic is: The emotional experiences of patients following removal of the eye
(Enucleation/Evisceration)

I hope to explore and describe the emotional experiences of patients following removal of an eye through enucleation and evisceration.

I will from time to time inform madam of all my actions and achievements.
I intend to use my off duty, Annual Leave and I will be paying for my tuition and books
Thanking you in advance.

I am.
Rose-Mercy Dikeledi Tlale.

East Grinstead
West Sussex
RH19 3DZ

Telephone: 01342 414000
Safe Haven Facsimile: 01342 414113

CORNEO-PLASTIC UNIT & EYE BANK

Sheraz M. Daya, MD,FACP,FACS, FRCS (Ed)
Director & Consultant Ophthalmic Surgeon

Raman Malhotra FRCOphth
Consultant Ophthalmologist and Oculoplastic Surgeon

Direct Fax No: 01342 414106

APPENDIX: D

Mr Malhotra (Oculo-Plastic Consultant)

RE: ROSE-MERCY DIKELEDI TLALE'S COMPLETION OF MASTER OF ARTS IN NURSING SCIENCE PROGRAMME THEORY AND EMBARKING ON DISSERTATION WITH THE UNIVERSITY OF SOUTH AFRICA

Dear Sir,

I hereby wish to make madam aware of the fact that my University requires me to undertake a Dissertation on the topic chosen by me from the unit I am presently working.

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Thanking you in advance.

I am.

Rose-Mercy Dikeledi Tlale.

APPENDIX: F



**UNIVERSITY OF SOUTH AFRICA
Health Studies Research & Ethics Committee
(HSREC)
College of Human Sciences
CLEARANCE CERTIFICATE**

Date of meeting: 28 February 2006

Project No: 0849-912-8

Project Title: The emotional experiences of patients following removal of the eye (Enucleation or Evisceration)

Researcher: Rose-Mercy Dikeledi Tlale

Supervisor/Promoter: Mrs LV Monareng

Joint Supervisor/Joint Promoter: Prof SM Mogotlane

Department: Health Studies

Degree: MA Cur

DECISION OF COMMITTEE

Approved 28 February 2006
Date:

Conditionally Approved

**Prof TR Mavundla
RESEARCH COORDINATOR: DEPARTMENT OF HEALTH STUDIES**

**Prof SM Mogotlane
ACADEMIC CHAIRPERSON: DEPARTMENT OF HEALTH STUDIES**

PLEASE QUOTE THE PROJECT NUMBER IN ALL ENQUIRES

APPENDIX: F

The Queen Victoria Hospital NHS Foundation Trust Research & Development Committee

NOTIFICATION OF APPROVAL OF THE PROPOSAL:

Title of Proposal	The emotional experiences of patients following removal of the eye (Enucleation or Evisceration)
Clinical Supervisor	R Malhotra
Lead Researcher(s)	Rose Tlale
Department(s)	Corneo-Plastic
Timescale	5 months

The R&D Committee has approved your proposal detailed above. The Trust accepts the role of Sponsor for this project. Before you can start your research you must sign and return this form to confirm that you have complied with the following:

1. I have obtained ethical approval for the project.

Please quote LREC approval number..... and date for completion.....

2. I and all researchers on the project are familiar and comply with the DOH “Research Governance Framework for Health and Social Care” – copies of this document are held by:

R&D Committee members
S Dawe, Research & Development Co-Ordinator
The QVH library
The DOH website: www.doh.gov.uk/research

3. *I and all researchers on the project comply with the Data Protection Act 1998 and with the Health and Safety at Work Act 1974.*
4. *I and all researchers on the project are familiar with and comply with the GMC publication “Research: the role and responsibilities of doctors”, the QVH Code of Practice for Researchers (available on the intranet) and with the QVH policy on Misconduct and Fraud in Research (available on the intranet).*
5. *I have agreed an interim report date ofwith my supervisor and with the Clinical Audit and Research Department.*
6. *All patients recruited will have the project Ethics number recorded on their PAS details (for instructions on how to do this see the intranet).*

7. *Any adverse events will be flagged up as research-related in the Trust's incident reporting system.*

Name of lead researcher

Rose-Mercy Dikeledi Tlale..... (please print)

Signed by lead researcher.....drmtlale

Date.....22 August 2006

Please send this completed form to Sarah Dawe, Research & Development Co-Ordinator.

APPENDIX G:


Central Office for Research Ethics Committees
(COREC)

ANNEXURE G

DECLARATION OF THE END OF A STUDY

(For all studies except clinical trials of investigational medicinal products)

To be completed in typescript by the Chief Investigator and submitted to the Research Ethics Committee that gave a favourable opinion of the research (“the main REC”) within 90 days of the conclusion of the study or within 15 days of early termination. For questions with Yes/No options please indicate answer in bold type.

1. Details of Chief Investigator

Name:	ROSE-MERCY DIKELEDI TLALE
Address:	QUEEN VICTORIA NHS FOUNDATION TRUST 3A MERIDIAN WAY, HOLTYE RD E.GRINSTEAD RH19 3DZ
Telephone:	01342- 311572 (H) 01342 414466/ 4470 (W)
E-mail:	rosetlale@aol.com
Fax:	01342- 414106

2. Details of study

Full title of study:	THE EMOTIONAL EXPERIENCES OF PATIENTS FOLLOWING REMOVAL OF THE EYE (ENUCLEATION / EVISCERATION)
Research sponsor:	QUEEN VICTORIA NHS FOUNDATION TRUST
Name of main REC:	MA Cur Dissertation
Main REC reference number:	06/Q1911/48

3. Study duration

Date study commenced:	28 TH FEBRUARY 2006
Date study ended:	30 TH NOVEMBER 2006
Did this study terminate prematurely?	Yes /No If yes please complete sections 4, 5 & 6, if no please go direct to section 7.

4. Circumstances of early termination

What is the justification for this early termination?	N/A
---	-----

5. Temporary halt

Is this a temporary halt to the study?	Yes / No
If yes, what is the justification for temporarily halting the study? When do you expect the study to re-start?	e. g. Safety, difficulties recruiting participants, trial has not commenced other reasons. N/A

6. Potential implications for research participants

Are there any potential implications for research participants as a result of terminating/halting the study prematurely? Please describe the steps taken to address them.	N/A
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7. Final report on the research

Is a summary of the final report on the research enclosed with this form?	Yes / No If no, please forward within 12 months of the end of the study.
---	---

8. Declaration

Signature of Chief Investigator:	Drmtlale
Print name:	ROSE-MERCY DIKELEDI TLALE
Date of submission:	30 TH NOVEMBER 2006